Stigma, Emotion Appraisal and the Family Environment as Predictors of Carer Burden for Relatives of Individuals who Meet the Diagnostic Criteria for Borderline Personality Disorder

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Introductory chapter

Issues with diagnosing

Within the UK many clinical psychologists have detached from the traditional medical model, choosing to discount diagnostic categories for a more holistic approach (British Psychological Society [BPS], 2013; Kinderman, Read, Moncrieff & Bentall, 2013). However, without a diagnosis, individuals can be denied access to services within the National Health Service (NHS; BPS, 2015). Additionally, without naming a 'condition' it can be difficult to group individuals with the same difficulties for the purposes of research. The author has reservations about accepting medical language such as disorder, symptoms and mental illness. While some people may find a diagnosis helpful because it conceptualises what has been happening to them and helps them see a way forward, others find that it is a barrier to recovery (BPS, 2015). It has been acknowledged that such labelling has been linked to heightened social stigma (Angermeyer & Matschinger, 2003; Szeto, Luong & Dobson, 2013). Given that this thesis has a focus on stigma it was difficult to decide on how to focus on this client group without using diagnostic categories. However, as the papers that were reviewed use diagnostic and medical language the same language has been used within the thesis. As this work was co-produced with an expert by experience the decision to adopt this language in line with current research was made collaboratively, although it was agreed that the use of such language remains something that needs to be challenged.

Difficulties diagnosing personality disorder

There are further issues with the tools used to diagnose that brings into question their validity and reliability (Hoffman & Burland, 2007; Walker, 2006; Kinderman et al., 2013). The Diagnostic and Statistical Manual fifth edition (DSM V; American Psychiatric Association [APA], 2013) identifies ten types of personality disorder, although individuals can meet the diagnostic criteria for more than just one personality disorder. For Borderline Personality

disorder (BPD), an individual must meet five out of nine criteria to receive a diagnosis. Therefore, two people with the same diagnosis could potentially only have one criterion in common. Furthermore, there is a lack of consensus on how to diagnose; in the UK, some clinicians use the DSM V (APA, 2013) while some use the ICD-10 (World Health Organisation [WHO], 1992) and diagnostic classification systems also vary between countries. This lack of consensus makes it difficult to define what is meant by BPD and to compare findings cross-culturally.

For the empirical study within this thesis, carers support individuals who may have been told by a clinician that they have a diagnosis of BPD, however; were not formally assessed. The title of the study aims to reflect this issue through stating that participants are supporting individuals who meet the diagnostic criteria for BPD. Participants needed to identify seven or more traits that met the criteria of a diagnosis for BPD, according to the DSM IV (American Psychiatric Association, 1994), using the McLean screening instrument for borderline personality disorder (MSI-BPD; Zanarini et al., 2003), adapted for carers (Goodman et al., 2011). As a comparator group was used in the study, this screening tool identified whether participants were allocated to the BPD group or the comparator group. Regardless of the diagnosis that the carer understood their relative to have, a score of seven or above on the screening tool placed individuals in the BPD group.

The thesis overview

This thesis contains an overview of the difficulties relatives experience when supporting individuals who meet the diagnostic criteria for BPD. It contains a systematic review and an empirical study, both of which will be prepared for publication and are presented in separate chapters.

Chapter one presents the findings from a systematic review of the empirical literature on the psychological and interpersonal factors impacting on family caregiver distress, prepared

as an article to be submitted for peer review publication to Clinical Psychology Review. This review focuses on relatives who support someone who meets the diagnostic criteria for any personality disorder. The chapter begins by briefly describing personality disorder and more specifically BPD, explaining why this type of personality disorder is the most researched. It describes our current understanding of caregiving, with a focus on caring for someone with a mental health difficulty. The chapter then outlines the rationale for the literature review and synthesises the findings from 13 studies meeting the inclusion criteria. The search process is described in detail to allow transparency and enable the search to be replicated. Of the 13 studies included in the review, seven used quantitative methods, five used qualitative methods and one used mixed methods. The review highlights factors that contribute to caregiver distress. The review concludes that there is a need to further investigate what factors predict carer burden for these relatives and whether this differs from relatives of individuals with other mental health difficulties.

Chapter two presents an empirical study which aims to identify whether stigma, perceived threat of strong emotions, and expressed emotion within the family environment predict carer burden. To highlight the unique carer burden of relatives of individuals who meet the diagnostic criteria for BPD, a comparator group of relatives of individuals with other mental health difficulties were also recruited to the study. The carer-recipient relationship was also considered as a factor impacting on carer burden.

The chapter critiques the current literature on caregiving, with a focus on our current understanding of supporting someone with a diagnosis of BPD. The chapter then presents the methodology and procedure used in the study. Hierarchical regression analyses were used to analyse the data collected from a range of questionnaires completed by 98 participants. The meaning of the findings, how these relate to previous literature and the clinical implications for effectively supporting relatives of individuals with a diagnosis of BPD are discussed. This

chapter is prepared as an article to be submitted for peer review publication to Clinical Psychology and Psychotherapy.

The information in the two chapters is supplemented with information in the appendices for purposes of examination, to include additional information about journal author guidelines and documentation given to participants.

References

American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington D.C: American Psychiatric Publishing.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington D.C: American Psychiatric Publishing.

Angermeyer, M.C., & Matschinger, H. (2003). The stigma of mental illness: Effects of labelling on public attitudes towards people with mental disorder. *Acta Psychiatrica Scandinavica*, *108*(4), 304–309.

British Psychological Society: Division of Clinical Psychology. (2013). *Classification of behaviour and experience in relation to functional psychiatric diagnoses: Time for a paradigm shift. The DCP Position Statement*. Leicester: British Psychological Society.

British Psychological Society: Division of Clinical Psychology. (2015). *Understanding psychiatric diagnosis in adult mental health.* Leicester: British Psychological Society.

Goodman, M., Patil, U., Triebwasser, J., Hoffman, P., Weinstein, Z. A., & New, A. (2011). Parental burden associated with borderline personality disorder in female offspring. *Journal of Personality Disorders*, *25*(1), 59–74.

Hoffman, P.D., & Burland, J. (2007). *Borderline personality disorder: A most misunderstood illness.* National Alliance for Borderline Personality Disorder. Retrieved from http://www.borderlinepersonalitydisorder.com/a-most-misunderstood-illness/

Kinderman, P., Read, J., Moncrieff, J., & Bentall, R. (2013). Drop the language of disorder. *Evidence-Based Mental Health, 16*(1), 2-3.

Szeto, A.C., Luong, D., & Dobson, K.S. (2013). Does labeling matter? An examination of attitudes and perceptions of labels for mental disorders. *Social Psychiatry and Psychiatric Epidemiology 48*(4), 659–671.

Walker, M.T. (2006). The social construction of mental illness and its implications for the recovery model. *International Journal of Psychosocial Rehabilitation, 10*(1), 71-87. Retrieved from http://www.psychosocial.com/IJPR_10/Social_Construction_of_MI_and_Implications_for_Recovery_Walker.html

World Health Organization. (1992). *The ICD-10 classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines*. Geneva: World Health Organization.

Zanarini, M. C., Vujanovic, A. A., Parachini, E.A., Boulanger, J. L., Frankenburg, F. R., & Hennen, J. (2003). A screening measure for BPD: The McLean screening instrument for borderline personality disorder (MSI-BPD). *Journal of Personality Disorders, 17*(6), 568-573. doi: 10.1521/pedi.17.6.568.25355

Chapter 1: Systematic Review

Exploring Factors Associated with Carer Distress for Family Members of Individuals who Meet the Diagnostic Criteria for a Personality Disorder: A Systematic Review.[1]

Jenna Kirtley

[1] Article prepared for submission to Clinical Psychology Review (Author guidelines in appendix A)

Abstract

Family caregivers are individuals who provide unpaid support to their family members with physical and/or mental health problems; a demanding role that may impact on a carer's own wellbeing. The author aimed to systematically review the caregiving experience of carers supporting a family member with a personality disorder diagnosis, focusing on factors linked to carer distress. The PRISMA systematic review method was followed. The search process was conducted between October and December 2016. The included studies were empirical, written in English and published between 1997 and 2016. The main inclusion criteria were family members supporting individuals with a personality disorder and factors contributing to carer distress. However, comparison studies between carers of individuals with a personality disorder diagnosis and carers of individuals with other mental health difficulties were also included. Reference lists were scanned and subject matter experts were consulted for further studies. Thirteen studies met inclusion criteria, representing data on 1,686 carers. The findings indicated that various factors were linked to carer distress including relationship conflict, financial strain, lack of adequate support from services, stigma and burden. The studies offer helpful insight into the experiences of these carers. Future research should aim to understand what predicts carer burden.

Keywords: Personality disorder, distress, burden, carer, family, mental health

Introduction

Borderline Personality Disorder

The most widely researched personality disorder, Borderline Personality Disorder (BPD), is defined in the Diagnostic and Statistical Manual of Mental Disorders fifth edition (DSM-V) as involving a pervasive pattern of instability within interpersonal relationships, poor self-image, affect dysregulation, and marked impulsivity (American Psychiatric Association, 2013). The accuracy and usefulness of this diagnosis is widely debateable (e.g., Hoffman & Burland, 2007; Walker, 2006). One argument about the accuracy of the diagnosis is that an individual must meet five out of nine criteria to receive a diagnosis of BPD, therefore two people with the same diagnosis could potentially only have one criterion in common. An alternative approach to understanding an individual's difficulties is through psychological formulation (Johnstone & Dallos, 2013). However, diagnostic language has been used within the literature, therefore to bring together studies that researched the same client group, the author will refer to BPD diagnosis throughout the review.

National Institute of Clinical Excellence (NICE) guidelines (2009) state that the prevalence of BPD in the UK is just under 1%, however; one UK study exploring the prevalence of BPD in community samples found 4.4% of the population met the criteria for BPD (Coid, Yang, Tyrer, Roberts & Ullrich, 2006). BPD is related to high levels of self-harm and suicide attempts, in association with other specified factors, therefore individuals with a diagnosis of BPD are more likely to present to services compared to those diagnosed with a different personality disorder (Blum et al., 2008; Zanarini, Frankenburg, Hennen, Reich & Silk, 2006). The frequent use of services may explain why most of the personality disorder literature focuses on BPD.

Caring in the UK

Over the last 25 years there has been a shift within the National Health Service (NHS) towards community care, resulting in a reduction of inpatient units across the UK. Care in the community often leads to pressure on family members to support individuals within their family who have additional needs. The Carer Strategy (Department of Health, 2010) proposes early identification of carers and support to maintain their physical and mental wellbeing. The Carers Act (UK Government Legislation, 2014) outlines that local authorities have a responsibility to assess the needs of carers. These legal and government frameworks exist to ensure good quality care and support for carers. However, the State of Caring report (Carers UK, 2016) has shown that carers still struggle to get the support they need to manage both their personal wellbeing and the caring role. In addition, Cleary, Freeman, Hunt and Walter (2005) found that only one-third of carers were satisfied with their involvement in service user care planning. Furthermore, a UK service evaluation found evidence of mental health services within the NHS failing to adequately support unpaid family carers of individuals with a diagnosis of BPD (Crawford & Rutter, 2007). The NICE guidelines (2009) state that it is essential families and carers are involved in the treatment planning of individuals with a personality disorder. Although policy identifies carers as essential in the care of individuals with mental health difficulties, there may be challenges in implementing this into practice.

Families of individuals with a diagnosis of BPD

As individuals with a diagnosis of BPD tend to express heightened emotions, it is expected that family members supporting individuals with a personality disorder will also experience distress. It may be that the wellbeing of carers of people with a diagnosis of BPD are more affected than those caring for individuals with other mental health difficulties, given the strong interpersonal component of this difficulty (Liebman & Burnette, 2013).

Support groups for families and carers with a diagnosis of schizophrenia have been

found to reduce carer distress, increase family functioning, and improve the caregiving relationship (Cuijpers, 1999; McFarlane, Link, Dushay, Crilly & Marchal, 1995; Goldstein & Miklowitz, 1995). Although research evaluating interventions with carers of individuals with a personality disorder is limited, that which has been done has shown promising results (Gunderson, 2008; Gunderson, Berkowitz & Ruiz-Sancho, 1997).

It is hopeful that recent research has begun to focus on the unique caring experience of relatives and carers of those diagnosed with personality disorders (Bailey & Grenyer, 2014). Therefore, it seems appropriate to systematically review and synthesise the emerging empirical literature on this topic, and to identify any gaps to be addressed in future research.

Method

Protocol

The review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) statement for reporting systematic reviews (Moher, Liberati, Tetzlaff, Altman & the PRISMA Group, 2009) and additional guidelines for conducting and reporting systematic reviews. The methods of data collection and the inclusion criteria were predetermined and documented in a protocol (see appendix B).

Data sources

There were three stages of identifying studies. First, databases were searched, then reference lists were scanned, and lastly subject matter experts (SMEs) were consulted. These phases were completed between October and December 2016.

Searching Electronic databases.

PsycINFO, Scopus, MEDLINE, and PubMed were searched individually for eligible studies. Search terms used for each database included (family carer OR informal carer OR family member) AND (personality disorder OR personality difficulties OR personality traits

OR borderline personality disorder) AND (*stress OR burden OR burnout OR coping OR strain).

Scanning reference lists.

Once studies were selected using the inclusion criteria, the reference lists of each of these studies were scanned for further eligible studies.

Consultation with subject matter experts.

A list of the included studies was sent to SMEs within the area of research, inviting contribution of any further studies that may meet the review inclusion criteria. SMEs were those who had authored or co-authored two or more included studies.

Study selection

One author reviewed the eligible studies and checked them against the following inclusion criteria:

1. Family members or family caregivers of persons with a personality disorder.
2. Carer distress (or related construct, such as burden, burnout, stress, strain, coping).
3. Information on contributing factors to carer distress.
4. Empirical published studies.
5. Published over the last 19 years (1997-2016). The International Personality Disorder Examination (Loranger, Janca & Sartorius, 1997) provided a uniform approach for assessing personality disorders for the DSM IV and ICD-10 classification systems in 1997. The decision for searching studies post 1997 was due to this assessment tool.
6. Articles published in the English language.

Inclusion for review required the study to meet criteria 1-6. Studies were also included if they compared carers of persons with a diagnosis of personality disorder with carers of persons with other mental health difficulties. Studies were excluded if they focused solely on evaluating

carer interventions and if the comparator groups consisted of cognitive difficulties, such as dementia, autism or a learning disability.

Data extraction and risk of bias

Varied methods of obtaining studies were used to reduce the risk of selection bias, including scanning reference lists and contacting SMEs. A second rater reviewed the final selected studies without knowledge of the authors, institutions, journal titles or publishers and agreed that all the studies met the inclusion criteria.

Once the final studies had been identified, one reviewer read the studies and extracted data. The data extracted can be found in Table 1 and includes information on authors, design, population, country of origin, participant characteristics, comparator, outcome measures used, methods, data analysis and a quality assessment score. Two reviewers assessed the quality of each study and cross-checked scores. As suggested by Barrett (2001), inter-rater reliability was checked using Cronbach's alpha. An acceptable inter-rater reliability score was found (α =.72). The overall quality assessment score was calculated as the mean of the two reviewers scores for each study.

Quality Assessment

The Quality Assessment tool (QATSDD; Sirriyeh, Lawton, Gardner & Armitage, 2011) was used to rate the quality of the final selected studies. This 16-item tool is an inclusive tool that allows reviewers to score qualitative and quantitative work using the same scale (see appendix C). The maximum score that could be assigned to any study was 42. The final studies in the review included both qualitative and quantitative studies, therefore this tool was an appropriate option. The NHS Centre for Reviews and Dissemination (2001) addressed the need to recognise the importance of qualitative research and how it can support and add depth to quantitatively designed studies within the same area.

Results

Search results

Electronic database searches resulted in the identification of 1,520 studies (1,415 studies with duplicates removed). Of these, 1383 were excluded as their titles or abstracts clearly indicated that they did not meet the inclusion criteria. Of the remaining 32 studies, 13 were excluded because they were not specific to personality disorder, two were excluded because they were not available in the English language, six were excluded because the studies focused solely on evaluating a carer intervention and one was excluded because it was not an empirical study. This stage therefore identified ten studies for inclusion in the systematic review.

The scanning of reference lists identified a total of 319 studies (276 studies after duplicates and studies already included were removed). Of these, 269 were excluded as their titles or abstracts clearly indicated that they did not meet the inclusion criteria. Of the remaining seven studies, three were excluded as they were not specific to carers and two were excluded as they focused on evaluating a carer intervention. Therefore, this phase resulted in two further studies being included in the systematic review. Two SMEs were identified and contacted. One expert did not respond to the invitation. The other expert suggested a potential further study, which met the inclusion criteria. Therefore, one further study was added at this stage, resulting in a total of 13 studies to be included in the systematic review. Figure 1 represents the flow of identified and eligible studies.

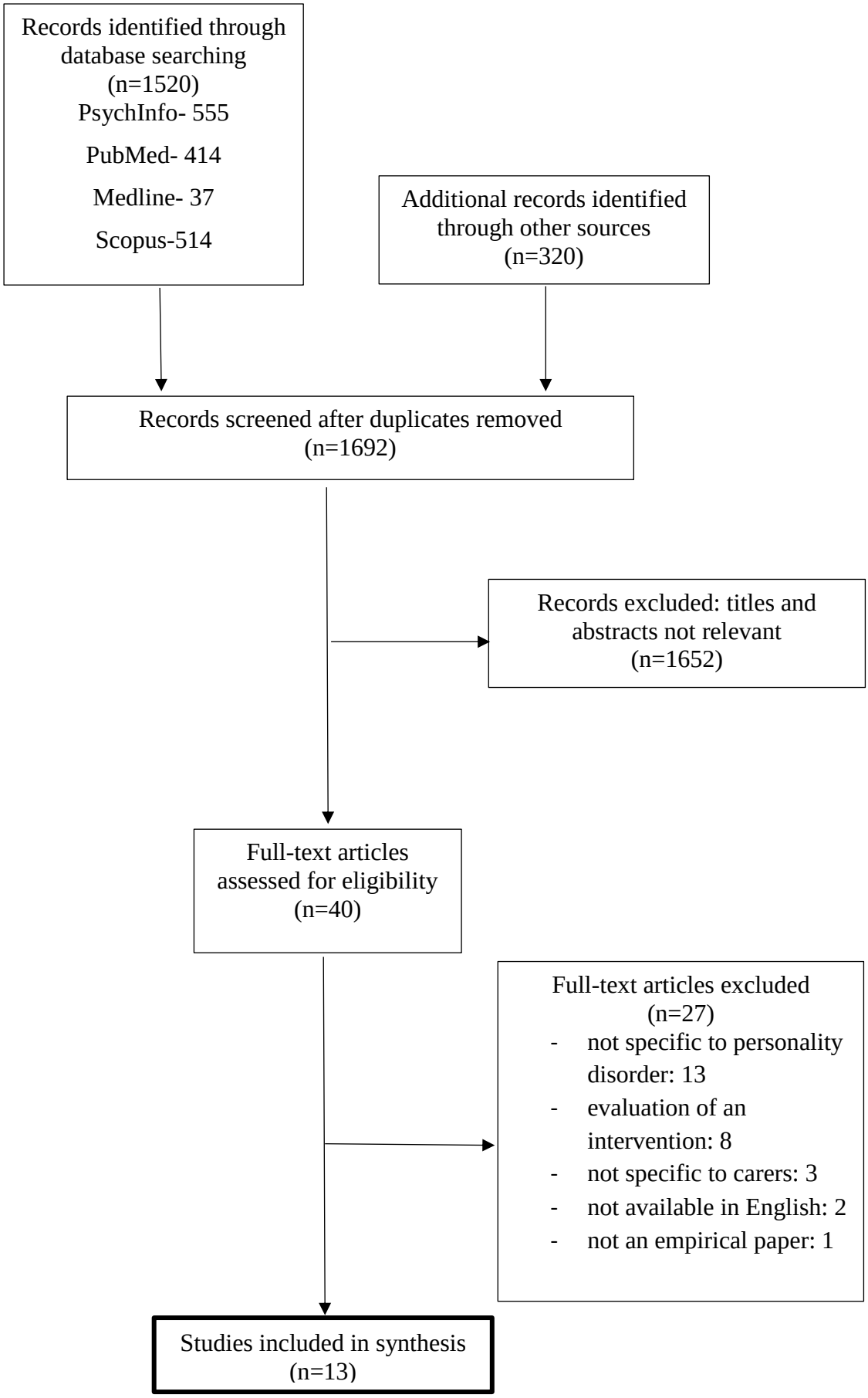

Figure 1. PRISMA flow chart demonstrating the results returned at each stage of the selection process.

Study characteristics

Of the 13 studies included in the review, seven used quantitative methods (Bailey & Grenyer, 2015; Goodman et al., 2011; Hadryś, Adamowski, & Kiejna, 2011; Hoffman et al., 2003; Schiers & Bok, 2007; Lawn & McMahon, 2015; Östman, Wallsten, & Kjellin, 2005), five used qualitative methods (Bauer, Döring, Schmidt, & Spießl, 2012; Buteau, Dawkins, & Hoffman, 2008; Dunne & Rogers, 2013; Ekdahl, Idvall, Samuelsson, & Perseius, 2011; Giffin, 2008) and one used mixed methods (Bailey & Grenyer, 2014). Since the included 13 studies were heterogeneous in both design and methodology, statistical aggregation in the form of a meta-analysis was not possible. Nine of the 13 studies focused solely on carers of individuals with BPD (Bailey & Grenyer, 2015; Buteau et al., 2008; Dunne & Rogers, 2013; Ekdahl et al., 2011; Giffin, 2008; Goodman et al., 2011; Hoffman et al., 2003; Schiers & Bok, 2007; Lawn & McMahon, 2015), while the other four studies focused on carers of individuals with unspecified personality disorder (Bailey & Grenyer, 2014; Bauer et al., 2012; Hadryś et al., 2011; Östman et al., 2005). Five of the thirteen studies compared carers of individuals with a diagnosis of personality disorder with carers of other mental health problems (Bailey & Grenyer, 2014; Bauer et al., 2012; Hadryś et al., 2011; Schiers & Bok, 2007; Östman et al., 2005). From the studies, only one was conducted in the UK (Dunne & Rogers, 2013).

Sample characteristics

The 13 included studies reported on a total of 1,686 carers. There was marginally more of one gender than the other (56% female). Asides from gender, the studies varied on the demographic information reported, therefore it was difficult to statistically represent the overall sample characteristics. However, most carers across the 13 studies were parents followed by partners/spouses. Age and ethnicity were not reported across all the studies.

Table 1. *Study characteristics*

Author (s)	Study Design	Study Population	Country	Participant Characteristics	Comparators	Outcome measures used	Method	Data Analysis Method	Quality score/ 42
Bailey & Grenyer (2014)	Cross sectional survey	Family carers of individuals with a diagnosis of a personality disorder. N=287	Australia	Male: 32.4% Female: 67.6% Parents: 37% Grown up children: 13.6% Siblings: 4.9% Partners: 36.9% Significant others: 7.6%	A comparison group for each measure was drawn from the published literature. This ranged from persons with Axis I disorders to healthy controls.	McLean Screening Instrument for Borderline Personality Disorder–Carer Version (MSI-BPD- C) Burden Assessment Scale Grief scale Mental health inventory (MHI) Difficulties with Emotion Regulation scale (DERS) Leximancer map	Questionnaires completed about burden, grief and mental health difficulties such as anxiety and depression. Carers responded with free text to the question "what impact has caring had on you, your life and relationships?"	Correlation using non-parametric test. Leximancer (content analysis program) to create a visual map of the relatedness of concepts from the qualitative text.	28
Bailey & Grenyer (2015)	Cross sectional survey	Family carers of individuals with a diagnosis of BPD. N=280	Australia	Female:71.1% Male: 28.9% Parents: 40.4% Partners: 32.9% Grown up children: 14.6% Siblings: 3.6% Significant others: 8.5%	None	McLean Screening Instrument for Borderline Personality Disorder–Carer Version (MSI-BPD- C) The Family Questionnaire (FQ) Mental Health Inventory (MHI) Burden Assessment Scale(BAS)	Questionnaires completed about expressed emotion, carer burden and mental health difficulties such as anxiety and depression.	Correlation using non-parametric test Kendall Tau.	30
Bauer et al. (2012)	Cross sectional interviews	Family carers of individuals with personality disorders. N=30	Germany	Female: 53.3% Male: 46.7%	General German population	Semi-structured interviews with narrative question "Which types of burden arise/arose for you from your relative's illness?"	Interviewed carers face to face.	Content analysis	21
Buteau et al. (2008)	Cross sectional interviews	Carers of individuals with a diagnosis of BPD N=12	Australia	Male: 2 Female: 10 Parents: 10 Spouse: 1 Sibling: 1	None	McLean Screening Instrument for Borderline Personality Disorder (MSI-BPD) Interview scripts designed with service user/carer input.	In-depth semi-structured interviews were conducted over the phone.	Thematic analysis	24

Dunne & Rogers (2013)	Cross sectional focus group	Carers of an individual with a diagnosis of BPD N=8	U.K.	Males: 5 Females: 3 Partners: 4 Parents: 3 Sibling: 1	None	Focus group topics covered: ‘‘The role of mental health services’’ and ‘‘experiences in the community.’’	Face to face focus group facilitated by a carer consultant	Thematic analysis	25
Ekdahl et al. (2011)	Cross sectional interviews	Carers of an individual with a diagnosis of BPD N=19	Sweden	Female: 14 Male: 5 Parents: 17 Partner: 1 Grown up child: 1	None	Free text questionnaire The interview topics were: “Experience of living close to someone with BPD” and “experience of coming into contact with services.”	Narrative group interviews	Content Analysis	31
Giffin (2008)	Cross sectional interviews	Parents of a daughter with a diagnosis of BPD N=4	Australia	Mothers: 3 Father: 1 Representing 4 families.	None	Interview questions: 'What is your experience of caring in relation to your daughter? “What is your experience of the mental health treatment approaches?'	Face to face unstructured in-depth interviewing	Grounded theory	26
Goodman et al. (2011)	Cross sectional Internet survey	Parents of daughters with BPD N=233	Inter-National	Female: 95% Male: 5% Mean age: 51	None	McLean Screening Instrument for Borderline Personality Disorder–Carer Version (MSI-BPD- C) Designed a questionnaire containing 109 questions.	Online questionnaire about parent’s mental health, carer burden and the financial costs associated with BPD.	Non-parametric partial correlations. ANOVA	26
Hadryś et al. (2011)	Cross sectional survey	Family members caring for relative with a mental health problem N=141	Poland	Parents of offspring with psychosis: 55 (mean age 51) Partners of individuals with	Psychosis and mood disorder	Patient Assessment: Polish version of the Involvement Evaluation Questionnaire (IEQ) Brief Psychiatric Rating Scale (BPRS v4.0)	Questionnaires about physical and mental health, quality of life and socio-	ANOVA Stepwise Regression Analysis	24

				mood disorder: 61 (mean age 42) Mother/daughter/ sibling of individuals with anxiety disorder including personality disorder: 25 (mean age 41)		Polish version of Groningen Social Disability Schedule (GSDS II) Manchester Short Assessment of Quality of Life (MANSA) Family member completed: Sociodemographic and Clinical History Inventory (CSCHI)	demographic factors of carers. Comparing a range of patient mental health difficulties.		
Hoffman et al. (2003)	Cross sectional interviews & surveys	Family members of individuals with BPD N=32	USA	Female: 59% Male: 41% Parents: 69% Mean age: 51	None	Patient assessment: SCID for DSM IV, BDI and Brief Symptom Checklist. Family members completed: BDI, Beck hopelessness Scale, Burden Assessment Scale, Brief Symptom Checklist, Camberwell Family Interview, Knowledge Assessment Interview.	In person interview and self-report surveys about level of knowledge of BPD, depression, burden and expressed emotion.	Multiple Regression Analysis	27
Lawn & McMahon (2015)	Cross sectional survey	Carers of people diagnosed with BPD N=121	Australia	Female: 76.5% Male: 23.5% 50–64 years old: 42% Parents:30%	None	A survey was developed by the Private Mental Health Consumer Carer Network (Australia)	Questionnaire completed about BPD diagnosis, impact of symptoms, contact with health services.	Chi-square	28
Östman et al. (2005)	Longitudinal (1986, 1991, 1997) Semi-structured measure	Relatives of someone with a mental health problem (personality disorder categorised as “other” alongside anorexia) N=455	Sweden	Female: 55% Male: 45% Mean age range: 40-59 Parents: 36% Partners: 28% Other: 36%	Psychosis & affective disorder	The instrument used was a semi-structured questionnaire, developed from clinical experiences.	Questionnaire completed about carer burden, support needs and involvement in care.	Kruskal– Wallis Mann–Whitney One way ANOVA	31

Schiers & Bok (2007)	Cross sectional survey	Carers of individuals with BPD N=64	Nether-lands	Female: 44 Mean age: 45 Biologically related (e.g. parents): 36 Unrelated (e.g. partners): 28	General Dutch population Biological vs unrelated carers	The Symptom Check List (SCL-90)	Questionnaire completed about carers mental health and returned via post.	One sample t-tests Multiple regression analyses	26

Quality assessment

Overall, the studies were of relatively average quality based on the QATSDD score. The range of scores from the studies were 21-31. The included studies had strengths in several important areas. All the studies had a clear description of the research problem and target population, offered detailed information on the recruitment data, and the method of data collection fit the research question well. The studies with lower quality assessment scores made no mention or very slight reference to major areas of research criteria. The main areas that were lacking were information about aims and objectives of the study, an explicit theoretical framework, evidence of sample size considered in terms of analysis and a representative sample size. Some of these studies did not offer a detailed account of procedure, justification for chosen analytical method, rationale and statistical assessment of data collection tools or a critical account of strengths and limitations of the study. Additionally, only three studies included service user/carer involvement in the study design (Buteau et al., 2008; Dunne & Rogers, 2013; Lawn & McMahon, 2015). The following studies were of better quality based on a quality assessment score above 26: Ekdahl et al. (2011); Östman et al. (2005); Bailey and Grenyer (2015); Lawn and McMahon (2015); Bailey and Grenyer (2014); Hoffman et al. (2003). The remaining seven studies scored 26 or below, with Bauer et al. (2012) receiving the lowest quality score of 21. Overall, there is a relatively small disparity between the quality of the included studies.

Main findings

Relationship conflict.

Of the 13 studies, eight refer to relationship conflict with the service user as a key factor contributing to higher levels of carer burden (Bailey & Grenyer, 2014, 2015; Bauer et al., 2012; Dunne & Rogers, 2013; Ekdahl et al., 2011; Giffin, 2008; Goodman et al., 2011; Lawn & McMahon, 2015). Bailey and Grenyer (2014) found that the caregiving role negatively affected family relationships, based on the results of the Leximancer concept map (Smith & Humphreys,

2006). Leximancer is a content analysis program used to create a visual map of the relatedness of concepts from qualitative text. In this study participants were asked to answer the following question using free text: "What impact has caring had on you, your life and relationships?" Further quantitative studies found that the caring role had a harmful impact on marriage and social life. Additionally, family conflict, rejection and relationship breakdown within relationships with other family members was common (Goodman et al., 2011; Lawn & Macmahon, 2015). These findings were consistent with the findings of qualitative studies (Bauer et al., 2012; Dunne & Rogers, 2013; Ekdahl et al., 2011; Giffin, 2008). One qualitative study found that carers felt a sense of uncertainty in their relationship with the care recipient (Bauer et al., 2012), which was similar to the finding of Ekdahl et al. (2011) who concluded that family members experienced "a life of tiptoeing" (p.71) through 24-hour duty and constant worry. Giffin (2008) highlighted that carers have strained relationships both with the person they care for and other family members. Similarly, Dunne and Rogers (2013) reported that carers experienced their relationship with the care recipient as painful and stressful, with little understanding or support from other family members.

Bailey and Grenyer (2014) recommended that future research could, "empirically explore the interpersonal experience of caregiving, to understand the relational dynamics potentially contributing to the experience of carer burden and mental health problems" (Grenyer, 2013, p.10-11). In their second study, Bailey and Grenyer (2015) found that for families who have a member with a diagnosis of BPD, the family environments were high in expressed emotion (EE). Expressed emotion can be defined as how much criticism, emotional over-involvement and warmth the carer expresses when discussing their relative with a mental health difficulty. It was found that 82.9% of carers expressed high levels of criticism (CC) and 69.6% of carers expressed high levels of emotional over-involvement (EOI). Elevated EOI correlated with higher carer burden and increased mental health problems for carers. Hoffman

et al. (2003) investigated whether EE predicted carer burden and found that there was no significant association between EOI and burden, however; the more knowledge a carer had about BPD, the greater the level of criticism.

Inadequate support from services.

Five studies found that inadequate support from services was linked to increased levels of carer distress (Buteau et al., 2008; Dunne & Rogers, 2013; Ekdahl et al., 2011; Giffin, 2008; Lawn & McMahon, 2015). Inadequate support included lack of available knowledge (Buteau et al., 2008; Dunne & Rogers, 2013), lack of involvement in care planning (Dunne & Rogers, 2013; Lawn & McMahon, 2015) and a stigmatising health care system (Buteau et al., 2008; Lawn & McMahon, 2015). Carers experienced poor staff attitudes, which resulted in a lack of trust in services (Dunne & Rogers, 2013; Ekdahl et al., 2011; Giffin, 2008). It has also been reported that there was no availability of support or support was withdrawn early, leaving carers feeling abandoned (Dunne & Rogers, 2013; Ekdahl et al., 2011; Lawn & McMahon, 2015). Additionally, it has been reported that abandonment was associated with higher levels of burnout (Dunne & Rogers, 2013).

Financial strain.

Four studies found that financial strain was a factor in contributing to carer distress (Buteau et al., 2008; Dunne & Rogers, 2013; Goodman et al., 2011; Hadryś et al., 2011). One of these studies concludes that the median cost of caregiving was U.S. $10,000 (Goodman et al., 2011) and another states that 66% of carers in the study worried about their financial status (Hadryś et al., 2011).

Stigma.

Three of the studies found a link between stigma and caregiver distress (Buteau et al., 2008; Ekdahl et al., 2011; Lawn & McMahon, 2015). In two of the studies carers reported experiencing discrimination when accessing services (Buteau et al., 2008; Lawn & McMahon,

2015). Additionally, one study found that participants experienced judgements from extended family members and friends, which led to feelings of powerlessness and a grieving for their past life (Ekdahl et al., 2011).

Wellbeing.

The studies showed that carers displayed a range of difficulties with their own mental health and wellbeing. Bailey and Grenyer (2014) found that carers showed signs that were linked to mood, anxiety, and posttraumatic stress disorders. Carers reported feelings of prolonged hopelessness (Buteau et al., 2008), powerlessness and guilt (Ekdahl et al., 2011). In one study the majority of carers reported that their emotional health was the most damaged, followed by their physical health (Goodman et al., 2011). It has also been found that greater knowledge of personality disorder diagnosis correlated with higher levels of depression, burden and hostility (Hoffman et al., 2003).

Other factors.

Studies reported that higher levels of burden were associated with greater number of service user impulsive behaviours and delusional beliefs (Goodman et al., 2011), older age of carer (Hadryś et al., 2011; Schiers & Bok, 2007) and greater number of hours spent in the caring role (Hadryś et al., 2011). Hadrys et al. (2011) found that the carer's age, level of acceptance of mental health difficulty of their relative, coping strategies and amount of daily activities they were involved in, explained the largest proportion of burden variance (23%). Additionally, the more time carers dedicated to their caregiving role, the higher the objective burden. Schiers and Bok (2007) investigated whether age and gender predicted carer symptoms scored on the Symptom Checklist (SCL-90-R; Derogatis, 1994). This is a relatively brief self-report questionnaire designed to evaluate a broad range of psychological problems and symptoms of psychopathology i.e., anxiety, depression, sleeping problems. The study found

that both significantly predicted depression, with older and female participants scoring highest on depression.

Comparisons.

Bailey and Grenyer (2014) reported that caregiver distress was higher in caregivers of individuals with personality disorder compared to other mental health problems. Bauer et al. (2012) and Schiers and Bok (2007) found that caregiver distress was greater compared to the general population. Ostman et al. (2005) reported that there were no differences between diagnostic subgroups. Hadrys et al. (2011) investigated whether a diagnosis was a predictor of carer burden and found burden to be independent of diagnosis, which is consistent with the Ostman et al. (2005) finding. However, these findings should be considered with caution because both studies included a small sample of carers of individuals with a personality disorder and categorised them with other disorders.

Some studies found differences between carers based on their relationship with the care recipient. One study found that partners experienced more burden compared to other carers (Östman et al., 2005) and another found that non-biologically related carers scored higher on hostility, while biologically related carers experienced greater levels of somatisation (Schiers & Bok, 2007). However, Schiers and Bok (2007) found that carer-recipient relationship was not a predictor of carer burden.

Measures used.

From the seven quantitative studies and the one mixed methods study, three studies (Bailey & Grenyer, 2014, 2015; Hoffman et al., 2003) used the Burden Assessment Scale (BAS; Reinhard, Gubman, Horwitz & Minsky, 1994), a 19-item measure of objective and subjective burden, where higher scores indicate higher levels of burden. The measure includes factors of disruptive activities, emotional distress, loss of time, financial strain and social functioning. Two studies (Bailey & Grenyer, 2014, 2015) used the Mental Health Inventory

(Cuijpers, Smits, Donker, ten Have & de Graaf, 2009), a 38-item measure for evaluating mental health issues such as anxiety, depression, behavioural control, positive effect, and general distress. Three studies created their own questionnaires (Goodman et al., 2011; Lawn & McMahon, 2015; Östman et al., 2005). Four studies used the Mclean screening instrument for BPD (Zanarini et al, 2003) to ensure participants met the inclusion criteria (Bailey & Grenyer, 2014, 2015; Buteau et al., 2008; Goodman et al., 2011). There was no further consistency across studies with regards to measures used.

Discussion

Summary

The present study aimed to systematically review and quality assess the available empirical data on the factors that contribute to caregivers' distress, focusing on carers of individuals with a diagnosis of personality disorder. Thirteen studies were eligible for the current review, based on the inclusion criteria.

Research in this area has increased in recent years, with the earliest study included in this review from 2003. Overall, the 13 included studies indicated that carers of persons with a personality diagnosis experienced burden, stigma, relationship conflict, financial strain, inadequate support from services and their own mental health problems, including anxiety, trauma, and stress. Studies were inconsistent on their findings about whether differences exist between carers across diagnostic subgroups and carer-recipient relationship. However, it was found that neither diagnosis nor carer-recipient relationship were predictors of carer burden (Hadrys et al., 2011; Schiers & Bok, 2007). There was also limited consistency on chosen measures; the most used was the BAS (Reinhard, Gubman, Horwitz & Minsky, 1994) and the Mclean screening instrument for BPD (Zanarini et al, 2003).

Findings associated with past literature

The findings of this systematic review suggest that carers struggle with a range of difficulties, impacting on their overall wellbeing, which is consistent with a recent systematic review (Bailey & Grenyer, 2013). They found that carers experienced elevated objective and subjective burden, grief, impaired empowerment, and mental health problems, including depression and anxiety. Some of the included studies support Crawford and Rutter (2007), who found that mental health services were inadequate in supporting unpaid family carers of persons with a diagnosis of BPD. However, there is only one UK study that suggests that current policy on supporting carers is not being successfully implemented into practice (Dunne & Rogers, 2013). Therefore, this could be explored further in future research within the UK.

Limitations of the studies

The highest quality assessment score given to a study in this review was 31 (out of a possible 42), highlighting some limitations to the studies included. Most studies had no comparator, however; from those that did, only three had a comparator group of individuals with other mental health problems (Bailey & Grenyer, 2014; Hadryś et al., 2011; Östman et al., 2005). Many of the studies offered a basic explanation of the procedure, choice of sample size and choice of analytical method; making the studies difficult to replicate (Bailey & Grenyer, 2014; Bauer et al., 2012; Buteau et al., 2008; Dunne & Rogers, 2013; Giffin, 2008; Hadryś et al., 2011; Schiers & Bok, 2007). Reliability assessments on the tools were not carried out on some studies (Buteau et al., 2008; Hadryś et al., 2011) and one did not use a standardised measure to assess burden (Goodman et al., 2011). Some of the studies had mostly or solely parent carers, meaning the sample was not representative of all carer types (Ekdahl et al., 2011; Giffin, 2008). Similarly, one study mixed personality disorder with anxiety disorders, with only a sample of five carers supporting someone with a personality disorder in a total sample of 141

(Hadrys et al., 2011). Another study mixed personality disorder with anorexia (Östman et al., 2005), limiting our understanding of the differences between diagnostic subgroups.

Service user/carer involvement in the design of the study was only mentioned in three studies (Buteau et al., 2008; Dunne & Rogers, 2013; Lawn & McMahon, 2015). It is important that service user/carers are involved in the research process to ensure researchers are investigating something that is worthwhile to the people who access services. Future research could consider including service user/carer involvement in the design of the study as this is a requirement of the National Institute for Health Research (Involve, 2017).

Methods of data collection varied. For example, one study conducted interviews over the phone, which could have made it difficult to analyse the data because they were missing non-verbal observations (Buteau et al., 2008). Another study was completed online (Goodman et al., 2011), which increases the level of missing data and can reduce reliability. One study excluded participants who could not travel for the interview, meaning participants had to be mobile and motivated (Dunne & Rogers, 2013) to be included.

Some important demographic information was missing from some studies, such as whether they lived with the care recipient (Lawn & McMahon, 2015) or length of time a participant had been in a relationship with the care recipient (Schiers & Bok, 2007). Most studies did not refer to ethnicity, however; it is important to consider that ethnicity could be a factor that contributes to carer burden. If studies reveal that participants are largely Caucasian then researchers may consider how to involve more ethnic minority groups into the research.

It was unclear whether a diagnosis of personality disorder had been given and how this was obtained, for example, using the ICD-10 or the DSM. Some studies relied on the opinion of the carers, reducing the reliability that the individuals met the criteria of a personality disorder. Four studies used the McLean screening instrument for BPD (Zanarini et al., 2003) to ensure participants met the inclusion criteria (Bailey & Grenyer, 2014, 2015; Buteau et al.,

2008; Goodman et al., 2011). This screening tool has shown good sensitivity (.81; percentage of correctly identified cases), specificity (.85; percentage of correctly identified non-cases) and excellent internal consistency (α = .90) for the Diagnostic and Statistical Manual of Mental Disorders fourth edition (DSM-IV) diagnostic criteria for BPD (Zanarini et al., 2003). It is commonly used in clinical practice and, although there are other effective screening tools, the McLean has the least items and was adapted for carers to identify observed traits of their relative (Goodman et al., 2011). Future research of these carers could consider using this instrument to create a consistent method for deciding inclusion criteria across studies.

Implications for future research

Due to the limited and inconsistent findings on comparisons, future research could consider carers of individuals that meet the criteria for a personality disorder to carers of individuals with other mental health problems. Additionally, future studies could also investigate whether there are differences between carer-recipient relationships, for example between parents and partners. This information would be helpful for modifying any current interventions to support the unique needs of these carers.

It is important to note that only one of the 13 included studies were conducted within the NHS in the UK (Dunne & Rogers, 2013). This study found that carers were dissatisfied with the services they received. Some of the other studies had similar findings, however; were based in other countries and therefore cannot be generalised to carers experiences within the UK. Further UK based studies exploring the experiences of carers of individuals with a diagnosis of personality disorder may be beneficial.

One of the six studies that scored above 26 on the QATSDD (Sirriyeh, Lawton, Gardner & Armitage, 2011) was qualitatively designed (Ekhdal et al., 2005). Although the sample size was small this was acceptable, given the nature of qualitative methodological approaches. The

study has offered some helpful insight into the experiences of carers and offers a focus for future research into predictors of carer burden.

One of the quantitative studies was consistent with the qualtivative findings of Buteau et al. (2008) and Ekdahl et al. (2011), highlighting that carers experienced discrimination (Lawn & Mcmahon, 2015). As only one quantitative study has begun to explore stigma, it would be worth considering this as a potential factor that predicts carer burden, considering the findings from the qualitative studies.

More than half of the studies highlighted that relationship conflict was a main factor in carer distress and two studies focused on the impact of EE on carer burden (Hoffman et al., 2003; Bailey & Grenyer, 2015). Bailey and Grenyer (2015) found high EOI and CC was related to greater levels of burden. However, Hoffman et al. (2011) found there was no significant association between EOI and burden, when investigating predictors of carer burden. Due to the inconsistent findings of the impact of EE, future research could continue to investigate this concept.

Methodological considerations

All included studies allow some empirical insight into the experience of supporting persons with a diagnosis of a personality disorder, mainly BPD. However, due to limited studies and differing aims and methods, there is scope to further investigate these carers. It would be helpful if further studies used the same measure of assessing carer burden to facilitate a meta-analysis in future systematic reviews in this area. It may be worth considering literature on caregiving in general, to obtain standardised measures and themes of carer wellbeing across the range of carers within mental health studies. This could guide decision making about measures within future studies on carers of individuals with a personality disorder diagnosis.

Limitations of review

The systematic review is limited in that it did not include studies that were not written in the English language. It also only included empirical studies, although PROSPERO and Cochrane Review Network were searched to ensure no past or current systematic reviews of the same title and aims existed. It also excluded studies that focused solely on pre- and post-intervention, which may have yielded some interesting findings and shed some light on which interventions may be of help to carers of individuals with a diagnosis of personality disorder. The systematic review also only focused on published papers. The grey literature may have presented with some papers that would have offered some contributions to the current findings. In future, it could be considered whether widening the scope would improve the quality of the review.

Conclusion

Although a range of psychological, emotional, and interpersonal difficulties have been identified as impacting on carer distress and burden most studies were either qualitative or preliminary in nature, focusing on correlations or exploring carer experiences. Some key themes including relationship conflict, stigma and carers emotional wellbeing emerged and therefore further research could focus on these key areas when investigating predictors of carer burden.

References

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington D.C: American Psychiatric Publishing.

Bailey, R. C., & Grenyer, B. F. S. (2013). Burden and support needs of carers of persons with borderline personality disorder: A systematic review. *Harvard Review of Psychiatry, 21*(5), 248-258.

Bailey, R. C., & Grenyer, B. F. S. (2014). Supporting a person with personality disorder: A study of carer burden and well-being. *Journal of Personality Disorders*, *28*(6), 1-14. doi:10.1016/j.apnu.2011.06.005

Bailey, R. C., & Grenyer, B. F. S. (2015). The relationship between expressed emotion and wellbeing for families and carers of a relative with borderline personality disorder. *Personality and Mental Health*, *9*(1), 21-32. doi:10.1002/pmh.1273

Barrett, P. (2001). *Assessing the reliability of rating data.* Retrieved from http://www.pbarrett.net/techpapers/rater.pdf

Bauer, R., Döring, A., Schmidt, T., & Spießl, H. (2012). "Mad or bad?": Burden on caregivers of patients with personality disorders. *Journal of Personality Disorders*, *26*(6), 956–971. doi: /10.1521/pedi.2012.26.6.956

Blum, N., Franklin, J., Hansel, R., McCormick, B., St. John, D., Pfohl, B., & ... Black, D. W. (2008). Relationship of age to symptom severity, psychiatric comorbidity and health care utilization in persons with borderline personality disorder. *Personality and Mental Health*, *2*(1), 25-34. doi:10.1002/pmh.26

Buteau, E., Dawkins, K., & Hoffman, P. (2008). In their own words: Improving services and hopefulness for families dealing with BPD. *Social Work in Mental Health*, *6*(2), 203–214. doi:10.1300/J200v06n01_16

Carers UK. (2016). *State of caring report.* London: carersuk.org. Retrieved from https://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-2016

Cleary, M., Freeman, A., Hunt, G. E., & Walter, G. (2005). What patients and carers want to know: An exploration of information and resource needs in adult mental health services. *Australian and New Zealand Journal of Psychiatry, 39*, 507–513.

Coid, J., Yang, M., Tyrer, P., Roberts, A., & Ullrich, S. (2006). Prevalence and correlates of personality disorder in Great Britain. *The British Journal of Psychiatry, 188*(5) 423-431. doi: 10.1192/bjp.188.5.423.

Crawford, M. J., & Rutter, D. (2007). Lessons learned from an evaluation of dedicated community-based services for people with personality disorder. *Mental Health Review Journal, 12*(4), 55-64. doi:10.1108/13619322200700039

Cuijpers, P. (1999). The effects of family interventions on relatives' burden: A meta-analysis. *Journal of Mental Health, 8*(3), 275–285.

Cuijpers, P., Smits, N., Donker, T., ten Have, M., & de Graaf, R. (2009). Screening for mood and anxiety disorders with the five-item, the three-item, and the two-item Mental Health Inventory. *Psychiatry Research, 168*, 250–255.

Department of Health. (2010). *Recognised, valued and supported: Next steps for the Carer's Strategy.* London: The stationary office. Retrieved from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213804/dh_122393.pdf

Derogatis, L. R. (1994). *SCL-90-R: Administration, scoring and procedures manual* (3rd ed.). Minneapolis, Minnesota: NCS Pearson.

Dunne, E., & Rogers, B. (2013). "It's us that have to deal with it seven days a week:" Carers and borderline personality disorder. *Community Mental Health Journal, 49*(6), 643–648. doi: /10.1007/s10597-012-9556-4

Ekdahl, S., Idvall, E., Samuelsson, M., & Perseius, K.I. (2011). A life tiptoeing: Being a significant other to persons with borderline personality disorder. *Archives of Psychiatric Nursing*, *25*(6), 69–76. doi:10.1016/j.apnu.2011.06.005

Giffin, J. (2008). Family experience of borderline personality disorder. *Australian and New Zealand Journal of Family Therapy*, *29*(3), 133-138. doi: 10.1375/anft.29.3.133

Goldstein, M. J., & Miklowitz, D. J. (1995). The effectiveness of psychoeducational family therapy in the treatment of schizophrenic disorders. *Journal of Marital & Family Therapy*, *21*(4), 361-376.

Goodman, M., Patil, U., Triebwasser, J., Hoffman, P., Weinstein, Z. A., & New, A. (2011). Parental burden associated with borderline personality disorder in female offspring. *Journal of Personality Disorders*, *25*(1), 59–74. doi: 10.0.5.241/pedi.2011.25.1.59

Gunderson, J. (2008). *Borderline personality disorder: A clinical guide* (2nd ed.). Arlington, Virginia: American Psychiatric Publishing.

Gunderson, J., Berkowitz, C., & Ruiz-Sancho, A. (1997). Families of borderline patients: A psychoeducational approach. *Bulletin of The Menninger Clinic*, *61*(4), 446-457.

Grenyer, B. F. S. (2013). Improved prognosis for borderline personality disorder: New treatment guidelines outline specific communication strategies that work. *Medical Journal of Australia*, *198*(9), 464–465.

Hadryś, T., Adamowski, T., & Kiejna, A. (2011). Mental disorder in Polish families: Is diagnosis a predictor of caregiver's burden? *Social Psychiatry & Psychiatric Epidemiology*, *46*(5), 363–372. doi:10.0.3.239/s00127-010-0200-8

Hoffman, P.D., & Burland, J. (2007). *Borderline personality disorder: A most misunderstood illness.* National Alliance for Borderline Persoanlity Disorder. Retrieved from http://www.borderlinepersonalitydisorder.com/a-most-misunderstood-illness/

Hoffman, P. D., Buteau, E., Hooley, J. M., Fruzzetti, A. E., & Bruce, M. L. (2003). Family

members' knowledge about borderline personality disorder: Correspondence with their levels of depression, burden, distress, and expressed emotion. *Family Process*, *42*(4), 469–478. doi: 10.1111/j.1545-5300.2003.00469.x

Involve. (2017). *Co-production.* National Institute for Health Research. Retrieved from http://www.invo.org.uk/current-work/co-production/

Johnstone, L., & Dallos, R. (2013). *Formulation in psychology and psychotherapy: Making sense of people's problems*. London, England: Routledge

Lawn, S., & McMahon, J. (2015). Experiences of family carers of people diagnosed with borderline personality disorder. *Journal of Psychiatric and Mental Health Nursing*, *22*(4), 234–243. doi: 10.1111/jpm.12193

Liebman, R., & Burnette, M. (2013). It's not you, it's me: An examination of clinician and client level influences on countertransference toward borderline personality disorder. *American Journal of Orthopsychiatry, 83*(1), 115-125. doi:10.1111/ajop.12002

Loranger, A., Janca, A., & Sartorius, N. (1997). *Assesment and diagnosis of personality disorder: The ICD-10 International Personality Disorder Examination (IPDE).* Cambridge: Cambridge University Press.

McFarlane, W., Link, B., Dushay, R., Crilly, J., & Marchal, J. (1995). Psychoeducational multiple family groups: Four-year relapse outcome in schizophrenia. *Family Process*, *34*(2), 127-144. doi:10.1111/j.1545-5300.1995.00127.x

Moher, D., Liberati, A., Tetzlaff, J., Altman, D.G., & PRISMA Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA Statement. *PLoS Med 6*(7). doi:10.1371/journal.pmed1000097

National Institute for Clinical Excellence. (2009). *Borderline personality disorder: Recognition and management.* Retrieved from https://www.nice.org.uk/guidance/CG78

NHS Centre for Reviews and Dissemination. (2001). *Undertaking systematic reviews of research on effectiveness: Guidance for those carrying out or commissioning reviews* (2nd ed.). York: Centre for Reviews and Dissemination.

Östman, M., Wallsten, T., & Kjellin, L. (2005). Family burden and relatives' participation in psychiatric care: Are the patient's diagnosis and the relation to the patient of importance? *International Journal of Social Psychiatry*, 51(4), 291–301. doi:10.1177/0020764005057395

Reinhard, S. C., Gubman, G. D., Horwitz, A. V., & Minsky, S. (1994). Burden assessment scale for families of the seriously mentally ill. *Evaluation and Program Planning, 17*(3), 261-269.

Schiers, J.G.M., & Bok, S. (2007). Psychological distress in caretakers or relatives of patients with borderline personality disorder. *International Journal of Social Psychiatry*, *53*(3), 195–203.

Sirriyeh, R., Lawton, R., Gardner, P., & Armitage, G. (2012b). Reviewing studies with diverse designs: The development and evaluation of a new tool. *Journal of Evaluation in Clinical Practice, 18*(4), 746-52. doi: 10.1111/j.1365-2753.2011.01662.x

Smith, A. E., & Humphreys, M. S. (2006). Evaluation of unsupervised semantic mapping of natural language with Leximancer concept mapping. *Behavior Research Methods, 38*(2), 262–279.

UK Government Legislation. (2014). *Care Act 2014.* Retrieved from http://www.legislation.gov.uk/ukpga/2014/23/pdfs/ukpga_20140023_en.pdf

Walker, M.T. (2006). The social construction of mental illness and its implications for the recovery model. *International Journal of Psychosocial Rehabilitation, 10*(1), 71-87. Retrieved from

http://www.psychosocial.com/IJPR_10/Social_Construction_of_MI_and_Implications_for_Recovery_Walker.html

Zanarini, M. C., Frankenburg, F. R., Hennen, J., Reich, D. B., & Silk, K. R. (2006). Prediction of the ten year course of borderline personality disorder. *The American Journal of Psychiatry, 163*(5), 827-832. doi:10.1176/appi.ajp.163.5.827

Zanarini, M. C., Vujanovic, A. A., Parachini, E. A., Boulanger, J. L., Frankenburg, F. R., & Hennen, J. (2003). A screening measure for BPD: The McLean screening instrument for borderline personality disorder (MSI-BPD). *Journal of Personality Disorders, 17*(6), 568-573. doi: 10.1521/pedi.17.6.568.25355

Chapter 2: Empirical paper

Stigma, Emotion Appraisal and the Family Environment as Predictors of Carer Burden for Relatives of Individuals who Meet the Diagnostic Criteria for Borderline Personality Disorder.[2]

[2] Article prepared for submission to Clinical Psychology & Psychotherapy, guidelines in appendix D

Abstract

Family caregivers may find themselves providing unpaid support to their family members with physical and/or mental health problems. This support can range from activities of daily living, such as personal care, to providing emotional and psychological support. There is some research exploring carers' experiences within the NHS in the UK but only one to date has focused specifically on carers of individuals with borderline personality disorder (BPD). Ninety-eight carers took part in a questionnaire-based study; 57 carers of individuals who meet the diagnostic criteria for BPD were compared to 41 carers of individuals with other mental health problems. The aim of the study was to investigate whether perceived stigma, perceived threat of strong emotions, and expressed emotion within the family environment predicted carer burden. The results showed that carers of those who met the diagnosis for BPD experienced higher levels of carer burden, stigma, expressed emotion (emotional over involvement and criticism) and perceived threat of strong emotions, compared to carers of individuals with other mental health difficulties. Emotional over involvement, criticism, carer group (BPD and mental health) and gender of participant were predictors of carer burden, with EOI explaining the most variance of burden. The authors conclude that a tailored intervention is needed for carers of individuals who meet the diagnostic criteria for BPD. The intervention should address interpersonal effectiveness, mentalisation and management of emotions. It is also suggested that future research should explore other potential predictors of carer burden including household income, social support and quality of life.

Keywords: borderline personality disorder, burden, carer, stigma, expressed emotion, emotion appraisal

Introduction

Borderline Personality Disorder

The most widely researched personality disorder, Borderline Personality Disorder (BPD), is defined in the Diagnostic and Statistical Manual of Mental Disorders fifth edition (DSM-V) as involving a pervasive pattern of instability within interpersonal relationships, poor self-image, affect dysregulation, and marked impulsivity (American Psychiatric Association, 2013) and is estimated to affect 4.4% of the UK population (Coid, Yang, Tyrer, Roberts & Ullrich, 2006). The diagnostic criteria for BPD has been criticised because it includes a wide range of difficulties and therefore comorbidity is high (Tyrer et al., 2007; Tyrer, 1988). This has resulted in difficulties understanding the diagnosis and unclear guidelines on both management and treatment (American Psychiatric Association, 2009; National Institute of Clinical Excellence, 2009; Tyrer & Silk, 2011).

There is a high rate of self-injurious behaviours and suicide attempts amongst individuals who meet the diagnostic criteria for BPD. It is estimated that 70-75% have engaged in at least one incident of life-threatening self-harm (Blum et al., 2008; Zanarini, Frankenburg, Hennen, Reich & Silk, 2006). Staff working with individuals who self-harm experience higher levels of stress and greater emotional distress compared to those working with individuals with depression (Bourke & Grenyer, 2010; Edwards, Burnard, Coyle, Folkergill & Hannigan, 2001). Therefore, it is possible that family members supporting individuals with a diagnosis of BPD, who are engaging in self-harming behaviours, will also experience a degree of emotional distress. Past research has shown that caring for someone with a diagnosis of BPD resulted in conflict, rejection and relationship breakdown with both the care recipient and other family members (Goodman et al., 2011; Lawn & Macmahon, 2015; Giffin, 2008). It has also been reported that carers feel a sense of uncertainty in their relationship with the care recipient (Bauer et al., 2012) and experience “a life of tiptoeing” (Ekdhal et al., 2011; p.71).

Caregiving in the UK

In the 2001 UK census, 6.8 million people were identified as carers in England, and of these, 1.5 million provide support for people with mental health difficulties (Mather & Green, 2002). Carer burden has been the focus of many studies on caregiving. Objective burden refers to practical difficulties such as financial problems, family conflict and limited social life, whereas subjective burden relates to the carers emotional experience of loss, sadness, anxiety, and coping (Ostman & Hansen, 2004). The combination of both objective and subjective burden, has shown that higher carer burden is associated with increased hours of contact with the care recipient (Schulz, O'Brien, Bookwala & Flessiner, 1995), poorer psychological health of the carer (Andren & Elmstahl, 2008), less ability to use healthy coping strategies and lower life satisfaction for the carer (Amirkhanyan & Wolf, 2006; Danhauer et al., 2004).

Most research on the impact of the caregiving role on carer wellbeing focuses on individuals that live with dementia, psychosis, and mood disorders, such as bipolar disorder (Shah, Wadoo & Latoo, 2010). There is currently limited research focusing on carers of individuals with a personality disorder diagnosis. To date, and to the author's knowledge, only 13 **e**mpirical studies; seven quantitative, five qualitative and one mixed method, have investigated the impact of caring for a relative with a diagnosis of personality disorder, with the majority focusing solely on BPD. The studies reported that carers experienced significant subjective and objective burden and greater psychological distress, compared to both the general population (Goodman et al., 2011; Scheirs & Bok, 2007) and carers of other mental health problems (Bailey & Grenyer, 2014). Qualitative research explored the experiences of carers of individuals with a diagnosis of BPD and found that distressing emotions such as grief, worry, guilt, and burden were linked to the caregiving role (Ekhdal, Idvall, Samuelsson & Perseius, 2011; Giffin, 2008). Many studies refer to relationship conflict with the service user as a key factor contributing to higher levels of carer burden (Bailey & Grenyer, 2014, 2015;

Bauer et al., 2012; Dunne & Rogers, 2013; Ekdahl et al., 2011; Giffin, 2008; Goodman et al., 2011; Lawn & McMahon, 2015).

Although it appears that carers of individuals with a diagnosis of BPD experience significant burden, evidence related to predictors of carer burden is less clear. Hoffman et al. (2003) investigated whether age and increased knowledge of BPD predicted carer burden and found that together they predicted 34% of variance in burden. A further two studies investigated whether age predicted carer burden, alongside other factors including diagnosis, carer coping, gender and carer-recipient relationship (Hadrys et al., 2011; Schiers & Bok, 2007). Both studies found that age predicted carer burden, however; they differed in their findings on gender and carer-recipient relationship. More research within the UK is needed to identify what predicts carer burden amongst this group of carers to establish ways to improve support interventions for this overlooked group of carers.

Current support interventions for carers

There are support groups for families and carers of people with a diagnosis of schizophrenia and evaluations of these groups have shown a reduction in carer distress, an increase in family functioning, and an improved caregiving relationship (Cuijpers, 1999; Goldstein & Miklowitz, 1995; McFarlane, Link, Dushay, Crilly & Marchal, 1995). Hoffman et al. (2005) evaluated a programme for families of individuals with a diagnosis of BPD called Family Connections, based on the strategies of standard Dialectical Behaviour Therapy (DBT). The programme provides current information and research on BPD, and both coping and family skills. The study showed significant reductions in grief and burden, and a significant increase in family members' confidence post intervention. Sanders and Pearce (2010) evaluated a small sample of family members taking part in a group programme called Oxford Friends and Family Empowerment (OFAFE) and found a non-significant reduction in isolation and burden, following the intervention. There is recognition that support interventions are needed for carers

of individuals with BPD and implementation of such interventions have had some success. However, the support needs experienced by families and carers of persons diagnosed with BPD remain under researched (Hoffman & Fruzzetti, 2007; Lefley, 2005; Bailey & Grenyer, 2014).

Stigma

Corrigan and Watson (2002) use the term public stigma to describe the ways in which members of the public discriminate against people with mental health problems. They describe self-stigma as the internalisation of this public stigma. Studies have investigated the impact of both internalised stigma and externalised stigma on mental health service users (Parle, 2012). Although there has been less focus on the impact on carers, past studies have shown that 43% to 92% report feeling stigmatised (Struening et al., 2001), perceived stigma is related to depression (Phelan, Bromet & Link, 1998) and withdrawal from support is common (Fadden, Bebbington & Kuipers, 1987).

Early research on families supporting someone with a diagnosis of BPD was subjugated by findings of family trauma, abuse, neglect and psychopathology (Masterson & Rinsley, 1975; Herman, Perry & Van de Kolk, 1989; Weaver & Clum; 1993). This led to the understanding that carers were the cause of their relative's difficulties and were unhelpful to their recovery (Gunderson, Berkowitz, & Ruiz- Sancho, 1997; Gunderson, 2008). Carers have reported experiencing stigma from both the wider community and mental health professionals, resulting in carer distress (Hoffman et al., 2005; Buteau et al., 2008; Ekdahl et al., 2011; Lawn & McMahon, 2015). Stigma has been associated with reduced help seeking and increased isolation (Fernando, Deane, Mcleod & Davis, 2017).

Expressed Emotion (EE)

EE focuses on the quality of interaction patterns among family caregivers and individuals with a mental health problem (Amaresha &Venkatasubramanian, 2012). EE has two subtypes: Criticism (CC) and emotional over-involvement (EOI). A high level of EE is a

strong predictor of relapse for individuals with a diagnosis of schizophrenia (Bebbington & Kuipers, 1994; Butzlaff & Hooley, 1998). In contrast, individuals with a diagnosis of BPD experience reduced symptoms of suicidality and self-harming behaviours when the family environment is elevated in EOI (Hooley & Hoffman, 1999). The authors theorised that the distinguishing features of EOI, such as the expression of overprotection, anxious concern and extreme emotional closeness, could be experienced as validating and therefore potentially helpful towards recovery for someone with a diagnosis of BPD.

Two studies to date investigated the impact of elevated EE on carers supporting individuals with a diagnosis of BPD. Bailey and Grenyer (2015) found that high levels of CC and EOI were associated with greater burden for carers. However, Hoffman et al. (2003) found no significant association between EOI and carer burden. There are conflicting results between the two studies and therefore it would be helpful to explore further the impact of EE on carers supporting relatives with a diagnosis of BPD.

Emotion appraisal

Appraisal theory states emotions are a result of our evaluations of events (Roseman & Smith, 2001). People appraise events differently, therefore the theory accounts for individual variances of emotional reactions to the same event (Lazarus, 1991). McCubbin and Sampson (2006) theorised that the extent to which an individual believes that having a certain emotion is dangerous would be related to heightened awareness of danger, attempts to avoid emotions, and the use of maladaptive coping methods. Their empirical study found that perceived threat from specific emotions significantly predicted obsessionality in a non-clinical sample. Smith, Wetterneck, Hart, Short and Bjorgvinsson (2012) investigated the appraisal of emotions of individuals with a diagnosis of Obsessive Compulsive Disorder (OCD). The results showed that both obsessional beliefs and emotion appraisal correlated with each of the symptom presentations. Emotion appraisal has also been shown to be associated with symptoms of

hoarding and a reduced ability to manage negative emotions amongst individuals who present with hoarding behaviours (Timpano, Shaw, Cougle & Fitch, 2014).

To the author's knowledge, no study to date has investigated whether negative appraisal of certain emotions can predict carer burden of carers of individuals with a BPD diagnosis. Individuals with a BPD diagnosis have difficulties with regulating strong emotions and controlling impulsive behaviours, such as self-harming (American Psychiatric Association, 2013). Since carers are likely to have regularly observed their relative struggling to manage strong emotions, they may negatively appraise this emotional experience.

Aims of current study

The aim was to explore whether stigma, CC, EOI and perceived threat of strong emotions were related to carer burden for carers of people who meet the diagnostic criteria for BPD and carers of individuals with other mental health problems. Furthermore, it was to identify whether these factors were strong predictors of carer burden.

Hypotheses

Four hypotheses were posed and are outlined below.

1. Higher levels of burden, stigma, EOI, CC and perceived threat of strong emotions would be reported by carers caring for individuals who meet the diagnostic criteria for BPD, compared to carers caring for individuals with other mental health problems.
2. Elevated EOI, CC, perceived stigma and perceived threat of strong emotions would be related to higher levels of carer burden.
3. Relationship to care recipient, gender and age would have an impact on the level of carer burden.
4. All independent variables would be strong predictors of carer burden.

Method

Participants

A total of 98 participants completed the study. Seventy-three were female (72.3%) and the mean age of participants was 56 years old (SD=13.44), with a wide age range from 23 to 82 years of age. The participants were mostly white British with only one participant identifying as mixed heritage. There were two modes of data collection; face to face or via telephone. Seventy-four participants completed the study face to face and 24 completed over the telephone. The participants were separated into two groups; the experimental group (BPD) and the comparator group (other mental health problems). Fifty-seven participants were in the BPD group (56.4%) and 41 participants were in the mental health group (43.6%). Participants were recruited from the North West of England.

Inclusion and exclusion criteria.

Participants below the age of 18 years of age were not recruited. To participate in the study participants needed to be a parent or partner caring for a family member who met the diagnostic criteria for BPD or experienced another mental health problem. Individuals supporting someone with cognitive difficulties such as autism, dementia or a learning disability, were excluded from the study. Participants who could not read and write English were excluded from the study. Carers in this study are defined as those having regular contact with their relative and are involved in offering support financially, emotionally, socially, and/or physically. Parent carers were mothers or fathers who were involved in the upbringing of their son/daughter; including biological, step, and adoptive parents. Partner carers were husbands/wives, civil partners, common law partners, or were in an intimate relationship to the person they cared for but lived separately. Therefore, carers of parents, siblings, other family members and friends were excluded from the study. When recruiting carers there was only one

carer recruited per individual cared for, rather than multiple people from the same family, to avoid clustering effects.

Design

The study used a cross sectional correlational design methodology with a convenience sample, using self-report questionnaires. The time taken to complete all measures was 20-30 minutes.

Power Calculation.

A medium effect size of f=0.15 was assumed for hierarchical regression analyses, based on Cohen's (1992) guidelines for behavioural sciences, so that 80% power could be achieved with an alpha of 0.05. A priori calculation was undertaken using G*power (Faul, Erdfelder, Buchner & Lang, 2009) to compute the minimum number of participants required to achieve adequate statistical power, considering group comparison and carer-recipient relationship as two separate variables. This indicated that a total sample size of 98 participants was needed for a hierarchical regression analysis. The researcher aimed to recruit 49 carers of individuals who met the diagnostic criteria of BPD and 49 comparison carers.

Service user/carer consultation.

A carer consultant, who was an expert by experience and worked within the NHS Trust, was appointed as a clinical advisor and co-author. The carer gave some initial feedback on study design, including the need to have face to face contact with the carers and to include stigma as a variable. The carer took an active role in recruitment, attended the ethics board meeting, and reviewed drafts of the thesis.

Ethics Approval.

The research received ethical approval and sponsorship from the University of Liverpool (Reference UoL001179) and further approval from The Greater Manchester Research Ethics Committee (Reference 15/NW/0957; IRAS ID 195190) and the relevant NHS

Trust Research and Development department (Reference S1516; see Appendix E for ethical approval documents).

Measures

Demographics.

A self-report demographic sheet was used to record information about the carer and the relationship with the care recipient (see Appendix F). The following was included: age; gender; ethnicity; employment status; carer-recipient relationship and living arrangements. The carer was also asked whether they had children or additional children (if they were the care recipient's parent). The carer recorded the service user's diagnosis if known and the service user's gender. These data were collated to allow analysis of the influence of these factors upon burden.

BPD screening tool.

The McLean Screening Instrument for Borderline Personality Disorder **(**MSI-BPD; Zanarini et al., 2003) is a ten-item measure of BPD symptoms, used as a screening instrument. The confirmation of seven or more items has shown good sensitivity (.81; percentage of correctly identified cases), specificity (.85; percentage of correctly identified non-cases) and excellent internal consistency (α = .90) for the Diagnostic and Statistical Manual of Mental Disorders fourth edition (DSM-IV; American Psychiatric Association, 1994) diagnostic criteria for BPD (Zanarini et al., 2003). It has been adapted in previous research for carers to identify observed traits of their relative (Goodman et al., 2011; Bailey & Grenyer, 2014, see appendix G). This screening measure was used to identify whether participants were assigned to the BPD group or the comparison group.

Burden.

The Burden Assessment scale (BAS; Reinhard, Gubman, Horwitz & Minsky, 1994, see appendix H) is a 19-item measure of objective and subjective burden, where higher scores

indicate higher levels of burden. The maximum score possible was 76. The measure includes factors of disruptive activities, emotional distress, loss of time, financial strain and social functioning (including significant changes in work, family and social life). This measure has been frequently used in studies on caregivers of individuals with mental health difficulties and has shown excellent reliability (α = .91; Reinhard et al., 1994). The current study obtained a similar reliability score (α = .89).

Expressed emotion.

The Family Questionnaire (TFQ; Wiedemann, Rayki, Feinstein & Hahlweg, 2002, see Appendix I) is a 20-item measure of EE in the family environment, which includes ten items for CC and ten items for EOI. The scoring of each item ranges from one (never/rarely) to four (very often). Higher total scores on each subscale indicate higher EE. It provides a cut-off point of 23 as an indication of high CC, and 27 for EOI. A good internal consistency of scores has been reported for CC (α =.87) and for EOI (α=.80; Dominguez-Martinez, Medina-Prodas, Kwapil & Barrantes-Vidal, 2014). The reliability scores within the current study were consistent with these previous scores; CC (α = .89) and EOI (α =.77).

Stigma.

The Devaluation of Consumer Families Scale (DCFS; Struening et al., 2001, see Appendix J) is a seven-item measure requesting participants to rate on a four-point Likert scale the degree to which they agree with each statement. The statements focus on perceptions of discrimination directed towards carers supporting individuals with mental health difficulties. High scores represent high perceived stigma. Good internal consistency was previously reported (α =.80; Perlick et al., 2007) and was also found in the current study (α =.80).

Emotion Appraisal.

The Perceived Threat from Emotions Questionnaire-Revised (PTEQ-R; McCubbin & Sampson, 2006) is a measure of beliefs about emotions using nine questions for each of the

eight sub-scales: happiness, sadness, anger, fear/anxiety, disgust, guilt, lust, and strong emotions in general. Responses are rated on a five-point scale ranging from not at all (0) to definitely (5). Question eight in each subscale asks whether the participant can identify that emotion and question nine in each subscale asks how often they feel that emotion. As these questions do not measure the threat of emotion, the overall scoring of threat of emotion is generated by adding the first seven items of each subscale, with higher scores indicating greater overall threat from emotion (maximum score=35). The PTEQ-R has demonstrated strong convergent validity with measures of mood, responsibility, and thought-action fusion (McCubbin & Sampson, 2006). The strong emotions sub-scale was used within the current study because of its theoretical coherence with research on carer experiences and personality disorder (see Appendix K). The strong emotions sub-scale demonstrated good internal consistency (α=.84; McCubbin & Sampson, 2006). The current study found a slightly lower internal consistency score, however this was still satisfactory (α = .76).

Procedure

Participants were informed about the research through the participant information sheet sent to them by the clinical advisor, which outlined the purpose of the study, the right to withdraw, confidentiality, contact details of the researcher and information on who to contact, should they feel distressed in relation to the study (see Appendix L). The clinical advisor recruited from carers who were on the waiting list to complete family skills training within the local NHS Foundation Trust. Although those recruited for the study had received no previous intervention from the service, they would be receiving support following the study. To maximise the number of participants recruited, the researcher contacted the Engagement and Participation team within the NHS Trust. The team forwarded a letter to the Trust's carers association, informing them of the study. If carers met the inclusion criteria and wished to take part in the study they were asked to contact the researcher directly via e-mail or telephone.

Potential participants were invited to meet with the researcher and clinical advisor at one of the NHS Trust site buildings, or to complete the measures over the phone. There was an opportunity to ask questions before completing a consent form (see Appendix M). Following the study, participants were thanked for their participation, reminded of the contact details of the researcher and asked whether they would like to receive information about the outcomes of the study.

Statistical Analysis Procedure

Due to the questionnaires being completed either face to face or via the telephone there were no missing data. The data were analysed using the IBM statistical package for social sciences (SPSS) version 19 (IBM Corp, 2010). Data were screened to check correct data entry through cross checking raw data with the database entry. Demographic information and descriptive statistics are reported. Prior to inferential analysis, parametric assumptions concerning normal distribution and homogeneity of variance were vigorously checked. Normality assumptions were tested using visual assessment of histograms, Q-Q plots, the Kolmogorov-Smirnov test and the Levene test. The variables BAS and EOI were skewed and the Kolmogorov-Smirnov result was significant, violating assumptions of normality. As transformation and standardising z-scores made no difference to the distribution, non-parametric tests were used for investigating differences between groups and for correlational analyses. The effect sizes (*r*) are reported to offer a standardised measure of the size of the effect observed, allowing for comparison to other studies (Field, 2009).

Multicollinearity values were checked to identify any significant relationships between the predictor variables, which would influence the validity of the model. This was done through analysis of the variance inflation factors (VIF) and tolerance values, which were produced by SPSS as part of multiple regression output. Results indicated that all predictor variables met satisfactory VIF and tolerance statistics as detailed in Field (2009) and therefore did not pose

significant multicollinearity issues. Histograms and scatterplots indicated a normal probability plot of the standardised residuals, confirming that assumptions of linearity were acceptable.

Multiple regression analysis using a block entry hierarchical method was chosen. The variables were entered in order, based on those hypothesised to affect the dependent variable the most. The demographic variable gender (value coded as 0 female, 1 male) was entered first followed by the binary predictor variable group (value coded as 0 MH, 1 BPD). As EOI and CC were found to correlate with carer burden in past research on personality difficulties (Bailey & Grenyer, 2014), these variables were entered next. This was followed by stigma because stigma and carer burden have been associated in studies of carers of relatives with other mental health problems (Struening et al., 2001; Perlick et al., 2007). As emotion appraisal had not been previously investigated in studies on carer burden, this predictor variable was entered last. Carer-recipient relationship did not significantly relate to carer burden during exploratory analysis and without a strong theoretical basis for including this variable it was excluded from the regression analysis. Once the important predictor variables were established from the initial six predictor model, the researcher re-ran the multiple regression analysis using a forward step-wise method, as recommended by Field (2009).

Results

Demographic characteristics

The responses from participants to the questions on the demographics sheet (see Appendix F) are shown in Table 1.

Table 1

Demographic information of carers and care recipient

Demographic item measured	N
Carers	
Employed	26
Children or additional children	70
Single parent	32
Live with care recipient	61
Parent Carer	60
Partner Carer	38
Care recipient	
Male	54
Female	44
Anxiety and/or depression diagnosis	21
BPD diagnosis	38
Bipolar diagnosis	12
Schizophrenia or schizoaffective diagnosis	12
Post-traumatic stress disorder diagnosis	3
OCD diagnosis	2
Unidentified/unknown diagnosis	10

Descriptive statistics

The mean and standard deviations for the total number of participants and each of the four groups (Parent BPD, Partner BPD, Parent mental health (MH) and Partner MH are presented in Table 2.

Table 2

Mean and standard deviation (SD) for the total number of participants (Pts) and for each of the four groups

	Mean (SD)				
	BAS	CC	EOI	DCFS	PTEQ-R
Total Pts	46.29 (13.35)	28.05 (6.80)	31.22 (5.00)	18.60 (23.56)	19.76 (6.12)
Parent BPD	52.36 (11.57)	29.94 (6.31)	32.76 (4.41)	19.03 (3.46)	20.88 (6.37)
Partner BPD	48.33 (13.56)	29.13 (6.28)	32.00 (4.39)	19.21 (3.77)	21.96 (5.10)
Parent MH	42.30 (11.41)	26.93 (7.23)	29.78 (5.26)	18.19 (3.33)	17.37 (6.62)
Partner MH	36.14 (13.17)	23.93 (6.49)	29.07 (5.89)	17.50 (3.99)	17.93 (5.34)

Comparing groups (hypothesis 1)

Burden.

The parent BPD group experienced significantly higher levels of burden than parent MH group, *U*=248, *z*=-2.94, *p*<.01, *r*=-.38 and partner MH group, *U*=86.5, *z*=-3.36, *p*<.01, *r*=-.49. The partner BPD group experienced significantly higher burden than the partner MH group, *U*=82, *z*=-2.60, *p*<.01, *r*=-.422. There were no significant differences between parent and partner groups between the diagnostic groups.

Expressed emotion.

The parent BPD group experienced significantly higher levels of EOI than parent MH group, *U*=304, *z*=-2.11, *p*<.05, *r*=-.27 and partner MH group, *U*=144, *z*=-2.03, *p*<.05, *r*=-.30. The parent BPD group also experienced significantly higher levels of CC than partner MH group, *U*=116, *z*=-2.68, *p*<.01, *r*=-.34. The partner BPD group experienced significantly higher levels of CC than the partner MH group, *U*=91, *z*=-2.34, *p*<.05, *r*=-.38.

Perceived threat of strong emotions.

The parent BPD group significantly negatively appraised strong emotions more than parent MH group, *U*=292.5, *z*=-2.28, *p*<.01, *r*=-.29. The partner BPD group significantly negatively appraised strong emotions more than partner MH group, *U*=93, *z*=-2.28, *p*<.05, *r*=-.37 and parent MH group, *U*=166.5, *z*=-2.98, *p*<.01, *r*=-.42.

Stigma.

There were no significant differences between any of the groups. Parent BPD group experienced a marginally higher level of perceived stigma compared to parent MH group, *U*=368, *z*=-1.16, *ns*, *r*=-.15 and partner MH group, *U*=185.5, *z*=-1.06, *ns*, *r*=-.15. Partner BPD group experienced a marginally higher level of perceived stigma compared to parent BPD group, *U*=395.5, *z*=-.01, *ns*, *r*=-.00 and a higher level of perceived stigma compared to partner MH group *U*=136.5, *z*=-.96, *ns*, *r*=-.16 and parent MH group *U*=279, *z*=-.85, *ns*, *r*=-.12.

Correlation analysis (hypothesis 2)

The correlation coefficients for the relationship between burden and each of the independent variables are presented in Table 3.

Table 3

Correlation coefficients of all variables

	Burden	Group	Carer Type	PTEQ	DCFS	EOI
CC	.62***	-.27 **	-.09	.40***	.27**	.60***
EOI	.68***	-.26**	-.05	.36***	.37***	
DCFS	.29**	-.15	.00	.20*		
PTEQ	.26**	-.33***	.10			
Carer type	-.11	-.08				
Group	-.39***					

Note. *** $p<.001$, ** $p<.01$, * $p<.05$.

There was a significant, moderate, negative relationship between carer group and burden. There was a significant, strong, positive relationship between CC and burden and EOI and burden. There was a significant, weaker, positive relationship between DCFS and burden and PTEQ and burden. There was no significant relationship between carer-recipient relationship and burden.

Age and gender (hypothesis 3)

To determine whether a relationship existed between burden and the demographics of participants (age and gender) Spearman's correlation analyses were undertaken. There was no significant relationship between age and burden ($r=.03$, *ns)*. However, there was a significant, moderate, negative relationship between gender and burden, $r= -.30$, $p<.001$. Therefore, gender was entered into the regression analyses.

Multiple regression analysis (hypothesis 4)

The results of the multiple regression analysis are shown in Table 4.

Table 4

Multiple regression analysis results for a four-predictor model

	B	SE B	β	R^2	ΔR^2	R^2adj
Step 1				.46		.45
Constant	-9.93	6.34				
EOI	1.80	0.20	.68***			
Step 2				.50	.04	.49
Constant	-8.18	6.16				
EOI	1.64	0.20	.61***			
Group	5.72	2.04	.21**			
Step 3				.52	0.2	.50
Constant	-4.03	6.38				
EOI	1.55	0.20	.58***			
Group	5.48	2.01	.20**			
Gender	-4.67	2.25	-.15*			
Step 4				.57	0.5	.55
Constant	-5.89	6.13				
EOI	1.14	0.24	.43***			
Group	4.76	1.94	.18*			
Gender	-4.21	2.16	-.14			
CC	0.53	0.17	.27**			

Note. *** $p<.001$, ** $p<.01$, * $p<.05$.

As shown in Table 4, the predictor variables EOI, group, gender and CC accounted for 57% of variance in burden, as indicated by R^2 in step 4. A significant result, indicated these factors made a significant improvement to the model's ability to account for the variance. If the model derived from the population rather than the sample it would account for 2% less variance in burden, indicated by the subtraction of R^2adj from R^2. In the initial six predictor model regression analysis, adding stigma and perceived threat of emotions did not lead to a significant improvement to the model as indicated by a non-significant result and no additional variance being accounted for (see appendix N for the multiple regression analysis results for the six-predictor model).

For this model, EOI ($t(93)=8.98$, $p<.001$), CC ($t(93)=3.10$, $p<.01$), group ($t(93)=2.80$, $p<.01$) and gender ($t(93)=-2.08$, $p<.05$) are significant predictors of carer burden. From the magnitude of the *t*-statistic and the smaller significance value we can see that EOI had the greatest impact and that gender had the least. The regression model significantly improved the ability to predict burden compared to using the mean ($f(93) =30.14$, $p<.001$).

Discussion

Summary of study and aims

The current study aimed to investigate predictors of carer burden for family caregivers of individuals who met the diagnostic criteria of BPD. It also compared those carers to carers supporting individuals with other mental health difficulties to establish if differences existed between groups of carers for burden, EOI, CC, stigma and perceived threat of strong emotions.

EOI.

Findings indicated a positive relationship between burden and EOI, therefore as the level of burden increased the level of EOI also increased. The regression analysis highlighted that EOI accounted for 46% of the total variance in carer burden, explaining the largest amount of variance.

When considering the literature, the current study supports the finding of Bailey and Grenyer (2014), that carers of individuals who met the diagnostic criteria for BPD experienced higher levels of EOI than carers of individuals with other mental health problems. The current study was the second study to consider EOI as a predictor of carer burden. The results show it explains a large amount of variance in carer burden, which is inconsistent with Hoffman et al. (2003) who found that there was no significant association between EOI and burden. The current study had a larger sample size compared to Hoffman et al. (2003), which may explain the difference between studies. However, due to these inconsistent findings, EOI needs to be explored further with this population.

Previous research found that high levels of EOI was associated with improved mood and a reduction in both suicidality and impulsive behaviours for the care recipient (Hooley & Hoffman, 1999). The study highlights the importance of emotional support for individuals with a diagnosis of BPD. However, studies on carers have shown that high levels of EOI lead to increased burden for carers. An intervention that focuses on mentalisation could improve a carer's understanding of the mind-set of their family member and how this is linked to their behaviour. This better understanding, alongside setting fixed and flexible boundaries, may improve the family environment for both carer and care recipient.

CC.

CC had a strong, positive relationship with burden and the regression analysis showed that CC accounted for 5% of the variance in burden. Partners and parents of individuals with a diagnosis of BPD scored significantly higher on levels of CC compared to partners of individuals with other mental health problems.

This finding is consistent with Bailey and Grenyer (2015) who found that families reported elevated CC and this was associated with greater carer burden. It may be that carers supporting someone with a diagnosis of BPD require further intervention to work on critical judgements.

Group.

Previous research comparing carers of individuals with a BPD diagnosis to other carers had varying findings. One study found no difference between carers of individuals with personality disorder and carers of individuals with other mental health problems (Ostman, Wallsten & Kjellin, 2005) and another concluded that diagnosis was independent from carer burden (Hadrys, Adamowski & Kiejna, 2011). However, one study found that burden and grief were significantly higher than that reported by carers of persons with other mental health problems (Bailey & Grenyer, 2014). The current study supports the latter, highlighting that

carers of individuals with BPD experience significantly higher levels of burden, EOI, CC and perceived threat of emotions. Change in burden was predicted by whether a participant was in the BPD group compared to the MH group, with significantly higher BAS scores associated with the BPD group (b=5.72, p<.01). Carers of people with a diagnosis of BPD may need more intensive programmes compared to other carers.

Demographics.

The association between burden and age were investigated. Previous studies have found that carer characteristics (age, level of acceptance of diagnosis, coping and number of daily activities) explained the largest proportion of burden variance, accounting for 23% (Hadrys et al., 2011) and carer age significantly predicted depression, with older participants scoring higher (Schiers & Bok, 2007). However, there was no significant relationship between age and burden in the current study.

There was a significant, moderate, negative relationship between gender and burden, with gender accounting for 2% of variance in burden. Change in burden was predicted by whether a participant was female compared to male, with significantly higher BAS scores associated with female participants (b= -4.67, p<.05). This is consistent with Schiers and Bok (2007) who found that female carers scored significantly higher on depression. In contrast, Hadrys et al. (2011) found that gender did not predict carer burden. However, this study only included five carers of individuals with a diagnosis of BPD, therefore the sample was not representative of these carers. A difference between males and females is not uncommon in research and it is important to be cautious when considering clinical implications of this finding. It is possible that female participants displayed higher levels of burden because they managed stress differently to male participants. It has been found in previous research that male carers tend to be more task focused, which allows them to distance themselves from stress (Draper, 2004).

Stigma.

There were no significant differences in stigma between groups, suggesting all participants experienced a similar level of perceived external stigma. There was a significant, weak, positive relationship between burden and stigma, however; stigma did not predict carer burden.

Past studies have shown that 43% to 92% of caregivers of people with mental health problems report feeling stigmatised (Struening et al., 2001) and that perceived stigma is associated with depression (Phelan et al., 1998) and withdrawal from support (Fadden et al., 1987). Despite participants informing the researcher that stigma had an impact on their wellbeing and previous literature on caregiving verifying the negative impact of stigma, the current study did not support this.

The devaluation of consumer family scale (DCFS) was selected to measure stigma because no other carer specific measure of perceived stigma could be found. The measure used hypothetical situations to address the concept of perceived stigma, therefore reducing the likelihood that participants would have drawn from their own experiences. Future research could consider co-producing a questionnaire with carers that focuses on their personal experiences of stigma, including self-stigma.

Threat of strong emotions.

This concept was not studied with the current population in previous research. However, previous studies on OCD and hoarding showed that emotion appraisal correlated with symptoms and a lower tolerance of negative emotions (Smith et al., 2012; Timpano & Shaw, 2014). In the current study there was a significant, weak, positive relationship between burden and threat of strong emotions. Therefore, the more a person negatively appraised their strong emotions, the greater the experience of carer burden. It was expected in the current study

that emotion appraisal would have predicted carer burden. However, it did not contribute to the variance of burden.

The parent and partner BPD groups significantly negatively appraised strong emotions more than the parent and partner MH groups. However, the partner BPD group negatively appraised strong emotions more than any other carers. When considering future interventions for carers supporting individuals with a diagnosis of BPD it would be helpful to target emotion management, perhaps through mindfulness practice.

Carer-recipient relationship.

There were no significant differences between parents and partners in either of the diagnostic groups and there was no significant relationship between carer-recipient relationship and burden. The findings of past research vary. Ostman et al. (2005) found that partner carers experienced higher levels of burden compared to other carers. In contrast, Hadrys et al. (2011) found that biological carers experienced higher levels of stress and worry compared to non-biological carers. However, Schiers and Bok (2007) found that carer-recipient relationship was not a predictor of carer burden, which is consistent with the current study. There is currently no indication that parent carers would need a different intervention than partner carers because the carer-recipient relationship had no impact on levels of burden experienced.

Limitations

Despite the inclusion criteria requirement that carers must not have received previous interventions linked to the BPD diagnosis, it is acknowledged that this is difficult to control for. Individuals may have received support from a carer centre or from family and friends. Therefore, the difference in the level of support may have been a confounding variable within the study.

Physical and or mental health of carers was not investigated in the current study. Past studies on caregiving show a link between physical health problems and depression as well as

increased rates of mental health problems and mortality of carers (Schulz, O'Brien, Bookwala, & Flessiner, 1995; Shaw et al., 1997; Baumgarten et al., 1992). Exploring carers' physical and mental health may be helpful when considering their capacity to support someone. However, it was decided that this approach leads into pathologising carers' difficulties rather than normalising the stressful experiences of the caring role. In this context, it is better to understand the transactional model of stress (Folkman & Lazarus, 1980). The model explains how stress exists when there is an imbalance between demands and ability to cope. Therefore, improving coping strategies and acceptance rather than focusing on changing the situation can reduce stress. Future research could consider measures of quality of life, well-being and coping strategies, rather than more disorder specific measures.

When allocating participants to groups, there was sometimes a conflict between the diagnosis given and the score on the screening tool. For example, some carers reported their family member had a diagnosis of schizophrenia or bipolar, however; they scored above the cut-off point for BPD. This relates to the problem discussed earlier about the lack of reliability of diagnosis.

Complexity, due to either comorbidity and/or varying degrees of intensity and frequency of symptoms, could also have been a confounding variable. Some individuals may have experienced increased number of crises compared to other individuals within the same group. Mental health functioning fluctuates and therefore it is difficult to select participants caring for someone with the same intensity and frequency of symptoms. However, it would be helpful to consider controlling for these variables in future research.

Participants were all white British, with one exception. A review of the caregiving literature identified differences in levels of stress, coping and accessing services among carers of different ethnic backgrounds (Connel, Janevic & Gallant, 2001). It would have been helpful to evaluate this within the current study but, due to the use of convenience sampling, the pool

available was white British. It is worth noting that the population of Liverpool consists of 90.4% white British, white other or white mixed people. Therefore, black and ethnic minority individuals make up only 9.6% of the population, which is below the national average (Office of National Statistics, 2014).

Strengths

The self-report measures were chosen to collect data on the variables because they are easy for participants to complete. It is a strength of the study that so many participants were recruited, fulfilling the original power calculation. The significant results likely occurred because of the chosen methodology. Group effect would be less meaningful in the context of a smaller sample, making the current study more generalisable.

Another strength of the study was the decision to complete questionnaires face to face or via telephone, rather than online or by post. Both approaches resulted in no missing data because the researcher could take participants through each question and clarify any wording. There is a disadvantage that participants may have had concerns about anonymity, however; feedback was that they found the process more personable. This approach was time consuming for the researcher during data collection phase, however; the lack of missing data made the data analysis stage easier.

A further strength, was the inclusion of a carer as a clinical advisor on the study. This ensured that the chosen variables were meaningful to the participants and that recruitment was done in a timely manner. It is essential that service user/carers are involved in research and practice to improve services and their involvement in research is a requirement of the National Institute for Health Research (Involve, 2017). However, it may have strengthened the current study if a group of carers had completed an initial consultation or a pilot study. The inclusion of more than one carer would have supported the decisions about what variables and measures to include.

The BAS has been used across many studies on carers and therefore the choice to include it in the current study has resulted in further consistency across studies. However, it may have been interesting to use a measure of quality of life and wellbeing, rather than focusing solely on burden. To improve both research and outcomes for this group of carers could begin by replicating studies using the same measures.

Clinical Implications

One suggestion for improving intervention for carers of individuals with a diagnosis of BPD would be to focus on interpersonal difficulties and emotion management. This could include improving mentalisation ability, assertiveness skills and an understanding of appropriate boundary setting. These components may help reduce levels of EOI and CC within the family environment. Furthermore, it may be beneficial to consider mindfulness practice. Mindfulness could improve carers' awareness of their thoughts, feelings and the world around them and keep them grounded in the present moment. Incorporating mindfulness practice into an intervention with carers may reduce carer burden and improve coping. As the study showed this group of carers have a higher level of perceived threat of strong emotions compared to other carers, mindfulness could be a useful way for them to recognise and experience these emotions, without trying to avoid or change them. Developing self-awareness and acceptance may also reduce levels of perceived stigma. However, clinicians could also challenge stigma within services, ensuring understanding of the experiences of carers and individuals with a diagnosis of BPD is improved, and their need for support acknowledged.

Key policies, such as the triangle of care (Carers Trust, 2013), outline how to improve engagement between professionals, family members and service users. A more inclusive attitude for carers and families should be promoted, where carers are listened to and offered consultation to improve the functioning of the family unit. It could be beneficial if there was less focus on the individual service user and more awareness of the family unit. However,

NICE guidelines (2011) outline that even if service users do not want their family members involved in their care, carers still need to be given information about the mental health problem and signposted to sources of support. This study supports current policy, highlighting that these carers need support in their caring role.

Suggestion for further research

This study contributes to a limited number of studies in this area and therefore it could be helpful for future researchers to consider what other factors predict carer burden for this group of carers. This study did not investigate household income or level of social support participants received, which has been found to have profound effects on caregiver outcomes (Baumgarten et al., 1992; Gallant & Connel, 1997). As care giving is associated with a decline in social support and increased isolation (Clyburn, Stones, Hadjistavropoulos & Tuokko, 2000), future research on the impact of household income and social support on carer burden would be interesting. The research may offer some guidance on carer allowance needs and an improved understanding of useful sources of social support.

More research is needed on what type of intervention these carers require. In line with the clinical implications, an intervention focused on tackling EOI, CC, stigma and emotion appraisal could be piloted with these carers. An evaluation of this intervention may reveal its effectiveness and guide future research and practice.

Considering that there is a strong interpersonal factor to caring for individuals who meet the diagnostic criteria for BPD it would be worthwhile to design a study that captures the perspectives of both the service user and carer. The repertory grid technique (Kelly, 1955) is a method for eliciting personal constructs with minimal intervention or interpretation by the therapist or researcher. The repertory grid includes an individual's list of constructs that are organised as bipolar dimensions, such as selfish/caring, and used to think about, evaluate and differentiate between elements (Walker & Winter 2007). Elements usually include self and

family members. Participants are invited to explore in what ways the elements are similar and in what ways they are different, using the list of personal constructs. The grid is a useful tool both in formal family research and in exploratory and therapeutic family interviewing because in a relatively brief time, a rich set of hypotheses can be generated (Beail, 1985). A study using repertory grids would be one way of understanding complex family dynamics and could improve communication within the family unit.

Conclusion

The findings of the current study illustrate that this group of carers suffer higher levels of burden compared to other carers and therefore may benefit from designated interventions. The study highlights that EOI and CC predict carer burden and future interventions could consider how to address these concepts. There are likely to be other predictors of carer burden and therefore further research could explore other variables including household income, social support and quality of life. As the NHS relies more on family members to support relatives with mental health difficulties, it could be beneficial to place importance on supporting the family unit. Investment in carer interventions could improve both the wellbeing of carers and care recipients and could potentially reduce the reliance on services.

References

Amaresha, A. C., & Venkatasubramanian, G. (2012). Expressed emotion in schizophrenia: An overview. *Indian Journal of Psychological Medicine, 34*(1), 12-20. doi:10.4103/0253-7176.96149

American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington D.C: American Psychiatric Publishing.

American Psychiatric Association. (2009). *Practice guidelines for the treatment of patients with borderline personality disorder*. Washington D.C: American Psychiatric Publishing.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington D.C: American Psychiatric Publishing.

Amirkhanyan, A. A., & Wolf, D. A. (2006). Parent care and the stress process: Findings from panel data. *Journal of Gerontology Series B: Psychological Sciences & Social Sciences, 61*(5), 248-255.

Andrén, S., & Elmståhl, S. (2008). The relationship between caregiver burden, caregivers' perceived health and their sense of coherence in caring for elders with dementia. *Journal of Clinical Nursing, 17*(6), 790-799. doi:10.1111/j.1365-2702.2007.02066.x

Bailey, R. C., & Grenyer, B. F. S. (2014). Supporting a person with personality disorder: A study of carer burden and well-being. *Journal of Personality Disorders*, *28*(6). doi: 10.1016/j.apnu.2011.06.005

Bailey, R. C., & Grenyer, B. F. S. (2015). Relationship between expressed emotion and well-being for families and carers of a relative with borderline personality disorder. *Personality and Mental Health, 9*(1), 21-32.

Bauer, R., Döring, A., Schmidt, T., & Spießl, H. (2012). "Mad or bad?": Burden on caregivers of patients with personality disorders. *Journal of Personality Disorders*, *26*(6), 956–

971. doi: /10.1521/pedi.2012.26.6.956

Baumgarten, M., Battista, R.N., Infante-Rivard, C., Hanley, J.A., Becker, R., & Gauthier, S. (1992). The psychological and physical health of family members caring for an elderly person with dementia. *Journal of Clinical Epidemiology, 45*(1),61-70.

Beail, N. (1985). An introduction to repertory grid technique. In N. Beail (Ed.), *Repertory Grid Technique and Personal Constructs: Applications in clinical and educational settings* (pp. 1–24). Kent: Croom Helm Ltd.

Bebbington, P., & Kuipers, L. (1994). The predictive utility of expressed emotion in schizophrenia: An aggregate analysis. *Psychological Medicine, 24*(3), 707-718.

Blum, N., Franklin, J., Hansel, R., McCormick, B., St. John, D., Pfohl, B., & ... Black, D. W. (2008). Relationship of age to symptom severity, psychiatric comorbidity and health care utilization in persons with borderline personality disorder. *Personality and Mental Health, 2*(1), 25-34. doi:10.1002/pmh.26

Bourke, M.E. & Grenyer, B.F.S. (2010). Psychotherapists' response to borderline personality disorder: A core conflictual relationship theme analysis. *Psychotherapy Research, 20*(6), 680-691.

Buteau, E., Dawkins, K., & Hoffman, P. (2008). In their own words: Improving services and hopefulness for families dealing with BPD. *Social Work in Mental Health, 6*(2), 203–214. doi:10.1300/J200v06n01_16

Butzlaff, R. L., & Hooley, J. M. (1998). Expressed emotion and psychiatric relapse. *Archives of General Psychiatry, 55*(6), 547-552. doi:10.1001/archpsyc.55.6.547.

Carers Trust. (2013). *The triangle of care. Carer's included: A guide to best practice in mental health care in England.* London: Carer's Trust. Retrieved from https://professionals.carers.org/sites/default/files/thetriangleofcare_guidetobestpracticeinmentalhealthcare_england.pdf

Clyburn, L. D., Stones, M. J., Hadjistavropoulos, T., & Tuokko, H. (2000). Predicting caregiver burden and depression in Alzheimer's disease. *The Journal of Gerontology: Series B: Psychological Sciences and Social Sciences, 55*(1), 2-13. doi:10.1093/geronb/55.1.S2

Cohen, J. (1992). A power primer. *Psychological Bulletin, 112*(1), 155-159. doi:10.1037/0033-2909.112.1.155

Coid, J., Yang, M., Tyrer, P., Roberts, A., & Ullrich, S. (2006). Prevalence and correlates of personality disorder in Great Britain. *The British Journal of Psychiatry, 188* (5) 423-431. doi 10.1192/bjp.188.5.423.

Connel, C.M., Janevic, M.R., & Gallant, M.P. (2001). The costs of caring: Impact of dementia on family caregivers. *Journal of Geriatric Psychiatry and Neurology, 14*, 179-187.

Corrigan, P., & Watson, A. (2002). The paradox of self-stigma and mental illness. *Clinical Psychology, Science and Practice, 9*(1), 35-53.

Cuijpers, P. (1999). The effects of family interventions on relatives' burden: A meta-analysis. *Journal of Mental Health, 8*(3), 275–285.

Danhauer, S.C., McCann, J.J., Gilley, D.W., Beckett, L.A., Bienias, J. L., & Evans, D.A. (2004). Do behavioural disturbances in persons with Alzheimer's disease predict caregiver depression over time? *Psychology and Aging, 19*(1), 198-202.

Dominguez-Martinez, T., Medina-Prodas, C., Kwapil, T. R., & Barrantes-Vidal, N. (2014). Relatives illness attributions mediate association of expressed emotion with early psychosis symptoms and functioning. *Psychiatry Research, 218*(1), 48-53.

Draper, B (2004). *Dealing with dementia: A guide to Alzheimer's disease and depression in caregivers of patients with dementia.* London: Allen & Unwin.

Dunne, E., & Rogers, B. (2013). "It's us that have to deal with it seven days a week:" Carers and borderline personality disorder. *Community Mental Health Journal, 49*(6), 643–

648. doi: /10.1007/s10597-012-9556-4

Edwards, D., Burnard, P., Coyle, D., Fothergill, A., & Hannigan, B. (2001). Stressors, moderators, and stress outcomes: Findings from the all Wales community mental health nurse study. *Journal of Psychiatric and Mental Health Nursing, 7*(6), 529–537.

Ekdahl, S., Idvall, E., Samuelsson, M., & Perseius, K.I. (2011). A life tiptoeing: Being a significant other to persons with borderline personality disorder. *Archives of Psychiatric Nursing*, *25*(6), 69–76.

Fadden, G., Bebbington, P., & Kuipers, L. (1987). Caring and its burdens: A study of the spouses of depressed patients. *The British Journal of Psychiatry, 151*(5), 660-667. doi:10.1192/bjp.151.5.660

Faul, F., Erdfelder, E., Buchner, A., & Lang, A. (2009). Statistical power analyses using G*Power 3.1: Tests for correlation and regression analyses. *Behavior Research Methods, 41*(4), 1149-1160. doi:10.3758/BRM.41.4.1149

Fernando, S. M., Deane, F. P., McLeod, H. J., & Davis, E. L. (2017). A carer burden and stigma in schizophrenia and affective disorders: Experiences from Sri Lanka. *Asian Journal of Psychiatry, 26,* 77-81. doi:10.1016/j.ajp.2017.01.023

Field, A. P. (2009). *Discovering statistics using SPSS.* London, England: SAGE.

Folkman, S., & Lazarus, R. S. (1980). An analysis of coping in a middle-aged community sample. *Journal of Health and Social Behavior, 21*(3), 219-239. doi:10.2307/2136617

Gallant, M.P., & Connel, C.M. (1997). Predictors of decreased self-care among spouse caregivers of older adults with dementing illnesses. *Journal of Aging and Health, 9*(3), 373-395.

Giffin, J. (2008). Family experience of borderline personality disorder. *Australian and New Zealand Journal of Family Therapy*, *29*(3), 133–138. http://doi.org/10.1375/anft.29.3.133

Goldstein, M. J., & Miklowitz, D. J. (1995). The effectiveness of psychoeducational family therapy in the treatment of schizophrenic disorders. *Journal of Marital & Family Therapy, 21*(4), 361-376.

Goodman, M., Patil, U., Triebwasser, J., Hoffman, P., Weinstein, Z. A., & New, A. (2011). Parental burden associated with borderline personality disorder in female offspring. *Journal of Personality Disorders*, *25*(1), 59–74. doi:10.0.5.241/pedi.2011.25.1.59

Gunderson, J. (2008). *Borderline personality disorder: A clinical guide* (2nd ed.). Arlington, Virginia: American Psychiatric Publishing.

Gunderson, J., Berkowitz, C., & Ruiz-Sancho, A. (1997). Families of borderline patients: A psychoeducational approach. *Bulletin of the Menninger Clinic, 61*(4), 446-457.

Hadryś, T., Adamowski, T., & Kiejna, A. (2011). Mental disorder in Polish families: Is diagnosis a predictor of caregiver's burden? *Social Psychiatry & Psychiatric Epidemiology*, *46*(5), 363–372. doi:10.0.3.239/s00127-010-0200-8

Herman, J. L., Perry, J. C., & Van de Kolk, B. A. (1989). Childhood trauma in borderline personality diosrder. *American Journal of Psychiatry, 146*, 490-495.

Hoffman, P. D., Buteau, E., Hooley, J. M., Fruzzetti, A. E., & Bruce, M. L. (2003). Family members' knowledge about borderline personality disorder: Correspondence with their levels of depression, burden, distress, and expressed emotion. *Family Process*, *42*(4), 469–478. doi: 10.1111/j.1545-5300.2003.00469.x

Hoffman, P.D., Fruzetti, A.E., Buteau, E., Neiditch, E.R., Penney, D., Bruce, M., … & Struening, E. (2005). Family connections: A pilot study of a family program for relatives of persons with borderline personality disorder. *Family Process*, *44*(2), 217–225.

Hoffman, P., & Fruzzetti, A. (2007). Advances in interventions for families with a relative with a personality disorder diagnosis. *Current Psychiatry Reports, 9*(1), 68-73. doi:10.1007/s11920-007-0012-z

Hooley, J. M., & Hoffman, P. D. (1999). Expressed emotion and clinical outcomes in borderline personality disorder. *The American Journal of Psychiatry, 156*(10), 1557-1562.

IBM Corp. (2010). *IBM SPSS Statistics for Windows, Version 19.0.* Armonk, NY: IBM Corp.

Involve. (2017). *Co-production.* National Institute for Health Research. Retrieved from http://www.invo.org.uk/current-work/co-production/

Kelly, G. A. (1955). *The psychology of personal constructs*. New York: W.W. Norton & Company.

Lawn, S., & McMahon, J. (2015). Experiences of family carers of people diagnosed with borderline personality disorder. *Journal of Psychiatric and Mental Health Nursing, 22*(4), 234–243. doi: 10.1111/jpm.12193

Lazarus, R.S. (1991). *Emotion and adaptation*. New York, NY: Oxford University Press.

Lefley, H. (2005). From family trauma to family support system. In J. G. Gunderson & P. D. Hoffman (Eds.), *Understanding and treating borderline personality disorder: A guide for professionals and families.* Arlington, Virginia: American Psychiatric Publishing.

Maher, J., & Green, H. (2002). *Carers 2000.* London: The Stationery Office.

Masterson, J., & Rinsley, D. (1975). The borderline syndrome: The role of the mother in the genesis and psychic structure of borderline personality disorder. *International Journal of Psychoanalysis, 56,* 163-177.

McCubbin, R. A., & Sampson, M. J. (2006). The relationship between obsessive compulsive symptoms and appraisals of emotional states. *Journal of Anxiety Disorders, 20*(1), 42-57.

Mcfarlane, W., Link, B., Dushay, R., Crilly, J., & Marchal, J. (1995). Psychoeducational multiple family groups: Four year relapse outcome in schizophrenia. *Family Process, 34*(2), 127-144. doi:10.1111/j.1545-5300.1995.00127.x

National Institute of Clinical Excellence. (2009). *Borderline personality disorder: Treatment and management: Key priorities for implementation.* Retrieved from http://www.nice.org.uk/CG78/

National Institute of Clinical Excellence. (2011). *Service user experience in adult mental health: Improving the experience of care for people using the adult NHS mental health services.* Retrieved from https://www.nice.org.uk/guidance/CG136/

Office for National Statistics. (2014). *Census of population in England and Wales, 2011.* London: Office for National Statistics.

Ostman, M., & Hansson, L. (2004). Appraisal of caregiving, burden and psychological distress in relatives of psychiatric inpatients. *European Psychiatry, 19*(7), 402-407.

Östman, M., Wallsten, T., & Kjellin, L. (2005). Family burden and relatives' participation in psychiatric care: Are the patient's diagnosis and the relation to the patient of importance? *International Journal of Social Psychiatry*, 51(4), 291–301. doi:10.1177/0020764005057395

Parle, S. (2012). How does stigma affect people with mental illness? *Nursing Times, 108*(28), 12-14.

Perlick, D. A., Miklowitz, D. J., Link, B. G., Struening, E., Kaczynski, R., Gonzalez, J., … Rosenheck, A. (2007). Perceived stigma and depression among caregivers of patients with bipolar. *British Journal of Psychiatry, 190*(6), 535-536.

Phelan, J., Bromet, E., & Link, B. (1998). Psychiatric illness and family stigma. *Schizophrenia Bulletin, 24*(1), 115-126.

Reinhard, S. C., Gubman, G. D., Horwitz, A. V., & Minsky, S. (1994). Burden assessment scale for families of the seriously mentally ill. *Evaluation and Program Planning, 17*(3), 261-269.

Roseman, I. J., & Smith, C. A. (2001). Appraisal Theory. In K. Scherer, A. Schorr, T. Johnstone (Eds.). *Appraisal processes in emotion: Theory, methods, research*. Oxford: Oxford University Press.

Sanders, S., & Pearce, S. (2010). The Oxford Friends and Family Empowerment (OFAFE) service: Support and education for those affected by friends or family with personality disorder. *Mental Health Review Journal, 15*(4), 58-62.

Schiers, J.G.M., & Bok, S. (2007). Psychological distress in caretakers or relatives of patients with borderline personality disorder. *International Journal of Social Psychiatry*, *53*(3), 195–203.

Schulz, R., O'Brien, A.T., Bookwala, J., & Flessiner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates and causes. *Gerontologist, 35*(6), 771-791.

Shah, A. J., Wadoo, O., & Latoo, J. (2010). Psychological distress in carers of people with mental disorders: Compared schizophrenia, dementia and mood disorders. *British Journal of Modern Psychiatry, 3*(3), 326-327.

Shaw, W. S., Semple, S. J., Ho, S., Irwin, M. R., Hauger, R. L., Grant, I., & Patterson, T. L. (1997). Longitudinal analysis of multiple indicators of health decline among spousal caregivers. *Annals of Behavioral Medicine, 19*(2), 101-109. doi:10.1007/BF02883326

Smith, A. H., Wetterneck, C. T., Hart, J. M., Short, M. B., & Björgvinsson, T. (2012). Differences in obsessional beliefs and emotion appraisal in obsessive compulsive symptom presentation. *Journal of Obsessive Compulsive and Related Disorders*, *1*(1), 54-61. doi:10.1016/j.jocrd.2011.11.003

Struening, E. L., Perlick, D. A., Link, B. G., Hellman, F., Herman, D. B., & Sirey, J. A. (2001). The extent to which caregivers believe most people devalue consumers and their families. *Psychiatric Services, 52*(12), *1633*-1638.

Timpano, K. R., Shaw, A. M., Cougle, J. R., & Fitch, K. E. (2014). A multifaceted assessment of emotional tolerance and intensity in hoarding. *Behavior Therapy, 45*(5), 690-699. doi:10.1016/j.beth.2014.04.002

Tyrer, P. (1988). *Personality disorders: Diagnosis, treatment and course.* London: Wright.

Tyrer, P., Coombs, N., Ibrahimi, F., Mathilakath, A., Bajaj, P., Ranger, M., . . . & Din, R. (2007). Critical developments in the assessment of personality disorder. *British Journal of Psychiatry, 190*(4), 51–59.

Tyrer, P., & Silk, K. R. (2011). A comparison of UK and US guidelines for drug treatment in borderline personality disorder. *International Review of Psychiatry, 23*(4), 388-394. doi:10.3109/09540261.2011.606540

Walker, B. M., & Winter, D. (2007). The elaboration of personal construct psychology. *Annual Review of Psychology, 58,* 453–477. doi:10.1146/annurev.psych.58.110405.085535

Weaver, T. L., & Clum, G. A. (1993). Early family environment and traumatic experiences associated with borderline personality disorder. *Journal of Consultant Clinical Psychology, 61,* 1068-1075.

Wiedemann, G., Rayki, O., Feinstein, E., & Hahlweg, K. (2002). The Family Questionnaire: Development and validation of a new self-report scale for assessing expressed emotion. *Psychiatry Research, 109*(3), 265-279.

Zanarini, M. C., Vujanovic, A. A., Parachini, E.A., Boulanger, J. L., Frankenburg, F. R., & Hennen, J. (2003). A screening measure for BPD: The McLean screening instrument for borderline personality disorder (MSI-BPD). *Journal of Personality Disorders, 17*(6), 568-573.

Zanarini, M. C., Frankenburg, F. R., Hennen, J., Reich, D. B., & Silk, K. R. (2006). Prediction of the ten-year course of borderline personality disorder. *The American Journal of Psychiatry, 163*(5), 827-832. doi:10.1176/appi.ajp.163.5.827

Appendix A: Author Guidelines: Clinical Psychology Review

For full author guidelines see https://www.elsevier.com/journals/clinical-psychology-review/0272-7358/guide-for-authors

Article structure

Manuscripts should be prepared according to the guidelines set forth in the Publication Manual of the American Psychological Association (6th ed., 2009). Of note, section headings should not be numbered.

Manuscripts should ordinarily not exceed 50 pages, *including* references and tabular material. Exceptions may be made with prior approval of the Editor in Chief.

Appendices

If there is more than one appendix, they should be identified as A, B, etc. Formulae and equations in appendices should be given separate numbering: Eq. (A.1), Eq. (A.2), etc.; in a subsequent appendix, Eq. (B.1) and so on. Similarly for tables and figures: Table A.1; Fig. A.1, etc.

Essential title page information

Title. Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible. **Note: The title page should be the first page of the manuscript document indicating the author's names and affiliations and the corresponding author's complete contact information.**

Abstract

A concise and factual abstract is required (not exceeding 200 words). This should be typed on a separate page following the title page. The abstract should state briefly the purpose of the research, the principal results and major conclusions.

Keywords

Immediately after the abstract, provide a maximum of 6 keywords, using American spelling and avoiding general and plural terms and multiple concepts (avoid, for example, 'and', 'of').

Figure captions

Ensure that each illustration has a caption. Supply captions separately, not attached to the figure. A caption should comprise a brief title (**not** on the figure itself) and a description of the illustration. Keep text in the illustrations themselves to a minimum but explain all symbols and abbreviations used.

Tables

Please submit tables as editable text and not as images. Tables can be placed either next to the relevant text in the article, or on separate page(s) at the end. Number tables consecutively in accordance with their appearance in the text and place any table notes below the table body. Be sparing in the use of tables and ensure that the data presented in them do not duplicate

results described elsewhere in the article. Please avoid using vertical rules and shading in table cells.

References

Citations in the text should follow the referencing style used by the American Psychological Association. You are referred to the Publication Manual of the American Psychological Association, Sixth Edition,

Citation in text
Please ensure that every reference cited in the text is also present in the reference list (and vice versa).

Reference style

References should be arranged first alphabetically and then further sorted chronologically if necessary. More than one reference from the same author(s) in the same year must be identified by the letters "a", "b", "c", etc., placed after the year of publication. **References should be formatted with a hanging indent (i.e., the first line of each reference is flush left while the subsequent lines are indented).**

Examples: Reference to a journal publication: Van der Geer, J., Hanraads, J. A. J., & Lupton R. A. (2000). The art of writing a scientific article. *Journal of Scientific Communications,* 163, 51-59.

Reference to a book: Strunk, W., Jr., &White, E. B. (1979). *The elements of style.* (3rd ed.). New York: Macmillan, (Chapter 4).

Appendix B: Systematic Review Protocol

Exploring factors associated with carer distress of family members of individuals who meet the diagnostic criteria for a personality disorder: A systematic review

Jenna Kirtley

Review question(s)

What psychological and interpersonal factors contribute to caregiver distress (relationship and emotional difficulties)?

If any comparison studies, do these factors differ between carer type (i.e. parent, sibling, partner) or diagnosis (i.e. depression, anxiety, bipolar, psychosis)?

What outcome measures are used for these factors? What are the quality of these measures?

(family carer OR informal carer OR family member) AND (personality disorder OR personality difficulties OR personality traits OR borderline personality disorder) AND (burden OR *stress OR burnout OR coping OR strain)

Searches

The following databases will be searched:

• PsycINFO

• Scopus

• MEDLINE

• PubMed.

The following inclusion criteria will be used:

1. Family members or family caregivers of persons with a personality disorder.
2. Carer distress (or related construct, such as burden, burnout, stress, strain, coping).
3. Information on contributing factors to carer distress.
4. Empirical published studies.
5. Published over the last 19 years (1997-2016).
6. Articles published in the English language.

Included: Comparison studies with other mental health difficulties

Excluded: Cognitive difficulties/organic such as learning disabilities or dementia. Also papers that focused solely on evaluating interventions with no investigation to which factors contribute to distress of caregiver.

Context

Should details of the article be absent or the reviewer uncertain in regard to an inclusion criterion, the reviewer will assume that the criterion is met, thereby increasing the likelihood that the full article be obtained for in depth screening.

Outcome(s)

Primary outcomes

The anticipated most important outcomes of included studies would be an understanding of factors considered to contribute to carer burden, therefore clarifying what constructs may still need to be investigated to develop a better understanding of carers needs. Particularly if there are any differing needs between carers of individuals with a personality disorder and carers of individuals with other mental health difficulties.

Secondary outcomes

The anticipated secondary outcomes of included studies would be validated measures of carer burden and other measures related to factors found to impact on burden.

Data extraction, (selection and coding)

Studies will be selected as per the inclusion criteria. All eligible studies (as determined by evaluating the study title and abstract to the inclusion criteria) will be obtained as full text and reviewed in further depth in relation to the inclusion criteria.

As per previous published protocol recommendations (Sutton, Abrams, Jones, Sheldon, & Song, 1998), two further methods of literature sourcing will be conducted, that of consultation with leading researchers and scanning reference lists of included articles. Leading researchers will be determined by being an author/co-author in 3 or more identified articles in the search of electronic databases stage, and will be sent the list of acquired studies and requested whether they know of any other relevant studies. All further articles obtained by these two techniques will be subject to the same inclusion criteria (outlined above).

One reviewer will be involved in identifying potential studies.

Risk of bias (quality) assessment

Bias will be reduced by using three methods of literature sourcing, as per previously published protocol recommendations, as outlined above.

It is anticipated that very few studies have been published on this topic, and therefore very few studies will be included as per the criteria and will be descriptive or preliminary in nature. Therefore it is unlikely that grading the studies as per empirical status will be appropriate.

Strategy for data synthesis

Obtained and relevant studies will be synthesised into a data extraction table with the following headings: Author(s), study design, study population, country, participant characteristics, comparators, outcome measures used, method, data analysis, quality assessment score. Due to the expected low numbers of studies acquired as per the inclusion criteria, it is unlikely that any other analysis will be appropriate.

Dissemination plans

Once completed, the review will be published in an appropriate peer reviewed journal. A leaflet will be created to give to all participants, informing them of the main results and recommendations for both future research and clinical practice.

Appendix C: Quality assessment tool and scoring guidance notes

Criteria	0 = Not at all	1 = Very slightly	2 = Moderately	3 = Complete
Explicit theoretical framework	No mention at all.	Reference to broad theoretical basis.	Reference to a specific theoretical basis.	Explicit statement of theoretical framework and/or constructs applied to the research.
Statement of aims/objectives in main body of report	No mention at all.	General reference to aim/objective at some point in the report including abstract.	Reference to broad aims/objectives in main body of report.	Explicit statement of aims/objectives in main body of report.
Clear description of research setting	No mention at all.	General description of research area and background, e.g. 'in primary care'.	General description of research problem in the target population, e.g. 'among GPs in primary care'.	Specific description of the research problem and target population in the context of the study, e.g. nurses and doctors from GP practices in the east midlands.
Evidence of sample size considered in terms of analysis	No mention at all.	Basic explanation for choice of sample size. Evidence that size of the sample has been considered in study design.	Evidence of consideration of sample size in terms of saturation/information redundancy or to fit generic analytical requirements.	Explicit statement of data being gathered until information redundancy/saturation was reached or to fit exact calculations for analytical requirements.
Representative sample of target group of a reasonable size	No statement of target group.	Sample is limited but represents some of the target group or representative but very small.	Sample is somewhat diverse but not entirely representative, e.g. inclusive of all age groups, experience but only one workplace. Requires discussion of target population to determine what sample is required to be representative.	Sample includes individuals to represent a cross section of the target population, considering factors such as experience, age and workplace.
Description of procedure for data collection	No mention at all.	Very basic and brief outline of data collection procedure, e.g. 'using a questionnaire distributed to staff'.	States each stage of data collection procedure but with limited detail, or states some stages in details but omits others.	Detailed description of each stage of the data collection procedure, including when, where and how data were gathered.
Rationale for choice of data collection tool(s)	No mention at all.	Very limited explanation for choice of data collection tool(s).	Basic explanation of rationale for choice of data collection tool(s), e.g. based on use in a prior similar study.	Detailed explanation of rationale for choice of data collection tool(s), e.g. relevance to the study aims and assessments of tool quality either statistically, e.g. for reliability & validity, or relevant qualitative assessment.
Detailed recruitment data	No mention at all.	Minimal recruitment data, e.g. no. of questionnaire sent and no. returned.	Some recruitment information but not complete account of the recruitment process, e.g. recruitment figures but no information on strategy used.	Complete data regarding no. approached, no. recruited, attrition data where relevant, method of recruitment.
Statistical assessment of reliability and validity of measurement tool(s) (Quantitative only)	No mention at all.	Reliability and validity of measurement tool(s) discussed, but not statistically assessed.	Some attempt to assess reliability and validity of measurement tool(s) but insufficient, e.g. attempt to establish test–retest reliability is unsuccessful but no action is taken.	Suitable and thorough statistical assessment of reliability and validity of measurement tool(s) with reference to the quality of evidence as a result of the measures used.
Fit between stated research question and method of data collection (Quantitative)	No research question stated.	Method of data collection can only address some aspects of the research question.	Method of data collection can address the research question but there is a more suitable alternative that could have been used or used in addition.	Method of data collection selected is the most suitable approach to attempt answer the research question
Fit between stated research question and format and content of data collection tool e.g. interview schedule (Qualitative)	No research question stated.	Structure and/or content only suitable to address the research question in some aspects or superficially.	Structure & content allows for data to be gathered broadly addressing the stated research question(s) but could benefit from greater detail.	Structure & content allows for detailed data to be gathered around all relevant issues required to address the stated research question(s).
Fit between research question and method of analysis	No mention at all.	Method of analysis can only address the research question basically or broadly.	Method of analysis can address the research question but there is a more suitable alternative that could have been used or used in addition to offer greater detail.	Method of analysis selected is the most suitable approach to attempt answer the research question in detail, e.g. for qualitative IPA preferable for experiences vs. content analysis to elicit frequency of occurrence of events, etc.
Good justification for analytical method selected	No mention at all.	Basic explanation for choice of analytical method	Fairly detailed explanation of choice of analytical method.	Detailed explanation for choice of analytical method based on nature of research question(s).
Assessment of reliability of analytical process (Qualitative only)	No mention at all.	More than one researcher involved in the analytical process but no further reliability assessment.	Limited attempt to assess reliability, e.g. reliance on one method.	Use of a range of methods to assess reliability, e.g. triangulation, multiple researchers, varying research backgrounds.
Evidence of user involvement in design	No mention at all.	Use of pilot study but no involvement in planning stages of study design.	Pilot study with feedback from users informing changes to the design.	Explicit consultation with steering group or statement or formal consultation with users in planning of study design.
Strengths and limitations critically discussed	No mention at all.	Very limited mention of strengths and limitations with omissions of many key issues.	Discussion of some of the key strengths and weaknesses of the study but not complete.	Discussion of strengths and limitations of all aspects of study including design, measures, procedure, sample & analysis.

Appendix D: Author Guidelines for Clinical Psychology & Psychotherapy

For full author guidelines see http://onlinelibrary.wiley.com/journal/10.1002/(ISSN)1099-0879/homepage/ForAuthors.html

No specified word count.

MANUSCRIPT STYLE

The language of the journal is English. 12-point type in one of the standard fonts: Times, Helvetica, or Courier is preferred. It is not necessary to double-line space your manuscript. Tables should be provided on separate pages after the reference list. Figures should be uploaded as separate figure files.

- During the submission process you must enter the full title, short title of up to 70 characters and names and affiliations of all authors. Give the full address, including email, telephone and fax, of the author who is to check the proofs.
- Include the name(s) of any **sponsor(s)** of the research contained in the paper, along with **grant number(s)** .
- Enter an **abstract** of up to 250 words for all articles [except book reviews]. An abstract is a concise summary of the whole paper, not just the conclusions, and is understandable without reference to the rest of the paper. It should contain no citation to other published work.
- All articles should include a **Key Practitioner Message** — 3-5 bullet points summarizing the relevance of the article to practice.
- Include up to six **keywords** that describe your paper for indexing purposes.

Types of Articles

- **Research Articles:** Substantial articles making a significant theoretical or empirical contribution.
- **Reviews**: Articles providing comprehensive reviews or meta-analyses with an emphasis on clinically relevant studies.

REFERENCE STYLE

In-text Citations
The APA system of citing sources indicates the author's last name and the date, in parentheses, within the text of the paper. Cite as follows:

1. **When the reference is to a work by two authors, cite both names each time the reference appears** .
   Example: Sexual-selection theory often has been used to explore patters of various insect matings (Alcock & Thornhill, 1983) . . . Alcock and Thornhill (1983) also demonstrate. . .
2. **When the reference is to a work by three to five authors, cite all the authors the first time the reference appears. In a subsequent reference, use the first author's last name followed by *et al* . (meaning "and others")** .
   Example: Patterns of byzantine intrigue have long plagued the internal politics of community college administration in Texas (Douglas *et al* ., 1997) When the reference is

to a work by six or more authors, use only the first author's name followed by *et al* . in the first and all subsequent references. The only exceptions to this rule are when some confusion might result because of similar names or the same author being cited. In that case, cite enough authors so that the distinction is clear.

Reference List

APA – American Psychological Association

References should be prepared according to the Publication Manual of the American Psychological Association (6th edition). This means in text citations should follow the author-date method whereby the author's last name and the year of publication for the source should appear in the text, for example, (Jones, 1998). The complete reference list should appear alphabetically by name at the end of the paper.

Appendix E: Anonymised letters of approval from DclinPsy Research Review Committee, University Sponsorship, Ethics Committee and NHS Trust.

DclinPsy Research Review Committee Approval

RE: Stigma, emotion appraisal and the family environment as predictors of carer burden for parents of individuals with borderline personality disorder traits

Dear

Thank you for your response to the reviewers' and Vice-Chair comments of your research proposal submitted to the D.Clin.Psychol. Research Review Committee (letter dated 13/09/15).

I can now confirm that your amended proposal (version 3, dated September 2015, submitted 13/9/15) meet the requirements of the committee and have been approved by the Committee Chair. Please contact the Research Director for final confirmation of your research and conference budget.

Please take this Chairs Action decision as final approval from the committee.

You may now progress to the next stages of your research.

I wish you well with your research project.

University Sponsorship Approval

HEALTH PARTNERS

22 October 2015

Sponsor Ref: UoL001179

Re: Sponsorship Approval

"Predictors of carer burden for carers of individuals with BPD - Stigma, emotion appraisal and the family environment as predictors of carer burden for carers of individuals with borderline personality disorder"

Dear

After consideration by the Chair of the JRO Non Interventional Sponsorship Sub Committee on 22nd October 2015 1 am pleased to confirm that the University of Liverpool is prepared to act as Sponsor under the Department of Health's Research Governance Framework for Health and Social Care 2 nd Edition (2005) for the above study.

The following documents have been received by the Joint Research Office

Document title	Version	Date
Protocol	Version 1	September 2015
Participant Information Sheet	Version 1	21st September 2015
Participant Consent Form	Version 1	21st September 2015
Outcome measures	No Version	No Date
Participant Debrief Sheet	Version 1	21st September 2015

Please note this letter does NOT allow you to commence recruitment to your study.
A notification of Sponsor Permission to Proceed will be issued when governance and regulatory requirements have been met. Please see Appendix 1 to this letter for a list of the documents required.

If you have not already applied for regulatory approvals through IRAS you may now do so at https://www.myresearchproiect.org.uk/Home.aspx.

Ethics Committee Approval

12 January 2016

Dear

Study title:	**Stigma, Emotion Appraisal and the Family Environment as Predictors of Carer Burden for carers of Individuals with Borderline Personality Disorder**
REC reference:	**15/NW/0957**
Protocol number:	**UoL001179**
IRAS project ID:	**195190**

Thank you for your letter of 12 January 2015, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager,

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study

NHS Trust Approval

Our Ref: S1516

13th January 2016

RE: NHS Trust permission to proceed

Project Title: "Predictors of carer burden for carers of individuals with BPD"

I am pleased to inform you that the above project has received research governance permission.

Please take the time to read through this letter carefully and contact me if you would like any further information. You will need this letter as proof of your permission.

Trust R&D permission covers all locations within the Trust; however you will only be allowed to recruit from the sites/services you have indicated in section 3 of the SSI application form. If you would like to expand recruitment into other services in the Trust that are not on the original SSI then you must contact the R&D department immediately to discuss this before doing so.

You also must ensure you have liaised with and obtained the agreement of individual service/ward managers before commencing recruitment in that service and you must contact the relevant service/ward managers prior to accessing the service to make an appointment to visit before you can commence your study in the Trust.

Please make sure that you take your Trust permission letter with you when accessing Trust premises and please include the Trust reference number on any correspondence/emails so that the services are assured permission has been granted.

Appendix F: Demographics sheet

Stigma, emotion appraisal and the family environment as predictors of carer burden

Please complete the following information about yourself.

Age……..

Gender……

Ethnicity…….

Are you currently employed?

Is the person you care for male or female?

Do you live with this person?

How many people currently live with you (including the person you care for if applicable)?

What is your relationship to this individual?

If you know the diagnosis of the person you are caring for please write this here……

Do you have children (or other children if you are a parent to the care-recipient)?

If you have children, do you consider yourself a single parent?

Appendix G: McLean Screening Instrument for BPD-Carer's Version

Please read the following questions and consider them in relation to the person you care for. Tick yes if the question is true of your family member.

	No	Yes
In your experience, do you perceive that your relative's closest relationships have been troubled by a lot of arguments or repeated breakups?		
Have you ever been concerned that your relative has deliberately hurt his/herself physically (e.g. punched, cut, burned his/herself), or attempted suicide?		
Do you perceive your relative to have at least two problems with impulsivity (e.g. eating binges, spending sprees, drinking too much, verbal outbursts)?		
Do you experience you relative to be extremely moody?		
Do you perceive your relative to feel angry a lot of the time, or experience your relative in an angry or sarcastic manner?		
Do you perceive your relative to be often distrustful of other people?		
In your experience, do you perceive your relative to frequently feel "unreal" or as if things around him/her are unreal?		
Do you perceive or experience your relative as feeling empty?		
Do you perceive your relative to feel that he/she has no idea of who he/she is or that he/she has no identity?		
In your experience, do you perceive your relative to make desperate efforts to avoid feeling or being abandoned (e.g. repeatedly calling someone to reassure his/herself that the person still cared, begged the person not to leave him/her, clung to another person physically)?		

Scoring guidelines: Each item is rated as a "1" if it is present and a "0" if it is absent, and items are totalled for possible scores ranging from 0 to 10. A score of 7 has been determined to be a good diagnostic cut-off, meaning that a score of 7 or higher indicates that the individual is likely to meet criteria for borderline personality disorder.

Appendix H: Burden Assessment Scale

Please consider whether, in the last four weeks, you have experienced any of the difficulties stated below and circle the number that best explains the frequency.

HAVE YOU IN THE LAST FOUR WEEKS?	N/A	Not at all	A little	Some	A lot
1. Had financial problems	0	1	2	3	4
2. Missed days at work (or school)	0	1	2	3	4
3. Found it difficult to concentrate on your own activities	0	1	2	3	4
4. Had to change your personal plans like taking a new job, or going on a holiday	0	1	2	3	4
5. Cut down on leisure time	0	1	2	3	4
6. Found the household routine was upset	0	1	2	3	4
7. Had less time to spend with friends	0	1	2	3	4
8. Neglected other family members' needs	0	1	2	3	4
9. Experienced family friction and arguments	0	1	2	3	4
10. Experienced friction with neighbours	0	1	2	3	4
11. Become embarrassed because of his/her behaviour	0	1	2	3	4
12. Felt guilty because you were not doing enough to help	0	1	2	3	4
13. Felt guilty because you felt responsible for causing his/her problem	0	1	2	3	4
14. Felt resentful because he/she made too many demands on you	0	1	2	3	4
15. Felt trapped by your care giving role	0	1	2	3	4
16. Were upset about how much he/she had changed from their former self	0	1	2	3	4
17. Worried about how your behaviour with him/her might make the illness worse	0	1	2	3	4
18. Worried about what the future holds for him/her	0	1	2	3	4
19. Found the stigma of the illness upsetting	0	1	2	3	4

Scoring guidelines: The scale range is 0= N/A (not applicable), 1= not at all, 2= a little, 3= some and 4= a lot. Total score of all items indicates level of burden. Higher scores indicate higher levels of burden (max score 76).

Appendix I: The Family Questionnaire

This questionnaire lists different ways in which families try to cope with everyday problems. For each item please indicate how often you have reacted to your family member in this way. Please respond to each question, and circle only one response per question. The scale range is 1=Never, 2=Rarely, 3=Often and 4=Very Often.

	Never	Rarely	Often	Very often
1. I tend to neglect myself because of him/her	1	2	3	4
2. I have to keep asking him/her to do things	1	2	3	4
3. I often think about what is to become of him/her	1	2	3	4
4. He/she irritates me	1	2	3	4
5. I keep thinking about the reasons for his/her illness	1	2	3	4
6. I have to try not to criticize him/her	1	2	3	4
7. I can't sleep because of him/her	1	2	3	4
8. It's hard for us to agree on things	1	2	3	4
9. When something about him/her bothers me, I keep it to myself	1	2	3	4
10. He/she does not appreciate what I do for him/her	1	2	3	4
11. I regard my own needs as less important	1	2	3	4
12. He/she sometimes gets on my nerves	1	2	3	4
13. I'm very worried about him/her	1	2	3	4
14. He/she does some things out of spite	1	2	3	4
15. I thought I would become ill myself	1	2	3	4
16. When he/she constantly wants something from me, it annoys me	1	2	3	4
17. He/she is an important part of my life	1	2	3	4
18. I have to insist that he/she behave differently	1	2	3	4
19. I have given up important things in order to be able to help him/her	1	2	3	4
20. I'm often angry with him/her	1	2	3	4

Scoring guidelines: The total score of the ten even items indicates level of Criticism (CC). A cut off score of 23 is considered high CC. The total score of the ten odd items indicates level of Emotional over involvement (EOI). A cut off score of 27 is considered high EOI.

Appendix J: Devaluation of Consumer Families Scale

This questionnaire refers to ways in which you think members of the public perceive you. For each item please indicate how much you agree with each statement. Please respond to each question, and circle only one response per question. The scale range is strongly agree, agree, disagree and strongly disagree.

1. Most people in my community would rather not be friends with families that have a relative who has mental health problems (living with them)

Strongly Agree Agree Disagree Strongly Disagree

2. Most people believe that parents of children with a mental health problem are just as responsible and caring as other parents

Strongly Agree Agree Disagree Strongly Disagree

3. Most people look down on families that have a member who has mental health problems living with them

Strongly Agree Agree Disagree Strongly Disagree

4. Most people believe that their friends would not visit them as often if a member of their family were hospitalised for a serious mental health problem

Strongly Agree Agree Disagree Strongly Disagree

5. Most people treat families with a member who has mental health problems in the same way they treat other families.

Strongly Agree Agree Disagree Strongly Disagree

6. Most people do not blame parents for the mental health problems of their children

Strongly Agree Agree Disagree Strongly Disagree

7. Most people would rather not visit families that have a member who has mental health problems

Strongly Agree Agree Disagree Strongly Disagree

Scoring guidelines: Items are scored as follows: 4, strongly agree; 3, agree; 2, disagree; 1 strongly disagree. High scores denote high stigma and are summed across items (max 28).

The following items are reversed: 2, 5, 6

Appendix K: Perceived threat of strong emotions subscale

Before answering, please think carefully about a few occasions when you have felt strong emotions and then indicate on the scale provided how you think about that emotion most of the time by placing a circle around the number that is most appropriate.

(8) STRONG EMOTION	Not at all	A little Bit	Moderately	Quite a bit	Definitely
1. Do you think it is dangerous to feel strong emotion?	1	2	3	4	5
2. Could strong emotion cause you to lose control and do things you regret later?	1	2	3	4	5
3. Is feeling strong emotion 'bad' (a sign of being evil or failing)?	1	2	3	4	5
4. Is it extremely important to stop yourself from feeling strong emotion?	1	2	3	4	5
5. Can feeling strong emotions be frightening?	1	2	3	4	5
6. When you feel strong emotion does it feel that it will last forever?	1	2	3	4	5
7. Could strong emotion overwhelm you so that you are unable to function?	1	2	3	4	5
8. Are you able to clearly identify what you mean by 'strong emotion'?	1	2	3	4	5
9. Do you feel strong emotion quite often?	1	2	3	4	5

Scoring guidelines: Question eight in each subscale asks whether the participant can identify that emotion and question nine in each subscale asks how often they feel that emotion. As these questions do not measure the threat of emotion, the overall scoring of threat of emotion is generated by adding the first seven items of each subscale, with higher scores indicating greater overall threat from emotion (maximum score = 35).

Appendix L: Participant information sheet

Stigma, emotion appraisal and the family environment as predictors of carer burden

Thank you for taking the time to consider participating in this research project. Before you decide whether you would like to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

This information sheet explains the purpose of the study and what will happen if you take part. If there is anything that is not clear or if you would like more information before you make a decision, please ask the researcher.

What is the purpose of the study?
Carers who are caring for people with mental health problems face a range of challenges and it is important for them to receive the right support from services. The person you care for may present with symptoms of depression, anxiety, bipolar, schizophrenia, eating disorder or personality disorder. It may be that you have wondered how best to support them or have found that you have struggled physically, mentally, emotionally or financially. There may be many factors within the caring role that has an impact on your own well-being. The aim of this study is to investigate whether 3 factors: perceived stigma, perceived threat of emotions and expressed emotion within the family environment, predict carer strain. By gaining awareness of what predicts carer burden we can tailor future interventions to better support carers in their caring role. The study will compare carers of individuals with borderline personality disorder traits to carers of individuals with other mental health problems. The comparison should highlight whether the same interventions can be applied to all carers or whether the focus of interventions will be dependent on the symptoms presented by the person you care for.

Why have I been asked to take part?
You have been asked to take part because you are caring for someone who has either personality disorder traits or other mental health problems.

Do I have to take part?
No. You can decide not to take part in the study. Your participation is entirely voluntary and you can stop taking part at any point without giving a reason. The results you have given up to the point you decide to withdraw may be used unless you request that they are destroyed. Your decision to take part or not will have no detrimental effect on the service you or the person you care for will receive from the

What would it involve?
If you agree to take part you will be asked to complete five short questionnaires. The questions will focus on how you cope with the mental health problem of the person you care for and how you experience the relationship with them.

Participation is expected to take about twenty five minutes. If you decide to take part you can complete the measures at the building within your catchment area. If you are attending a peer support training programme or a service user involvement scheme meeting, it can be arranged for you to complete the questionnaires before you meet. You would be asked to attend 45 minutes before the programme/meeting starts. Alternatively, options of different

dates and times can be offered to you if you prefer to complete the study on a different day to the programme/meeting. Travel expenses will be reimbursed if you choose to attend on a different day.

Will my taking part in the study be kept confidential?
Yes. All information you provide will be kept completely confidential. All personal information (e.g. your name, the name of the service) or anything else which might identify you will be removed so that no-one will know who you are. The information that you provide will **not** be shared with anyone in the service. No names will be used in any reports that are written.

The only exception to confidentiality is if the information that you provide suggests that you or someone else may be at risk of harm. In the extremely rare circumstances when this does happen the researcher will make every effort to discuss this with you first.

What are the possible benefits of taking part?
You will not benefit from taking part in the study. However, any information that you give us can help us to improve clinical guidance about how to help people and their families when living with personality disorder or other mental health problems.

Are there any risks/disadvantages to helping with this research?
There are no known risks to taking part in this research the only disadvantage to you will be the time it takes to participate which is estimated to be about 20-30 minutes.

Who has reviewed the study?
All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and approved by Ethics Committee.

Who has funded this study?
This study has been funded by

What will happen to the results of the study?
The results of this study will be written up as a thesis which is in partial fulfilment of the principal researcher's qualification of Doctor of Clinical Psychology. In addition, it is hoped that it will be written up as publication in a relevant scientific journal and presented at a conference. However, you will not be identifiable in any publication that is produced.

At the end of your participation the researcher will ask you whether you would like to be sent a summary of the results when the research has been completed. If you would like a copy of the results she will take an address from you.

What if I am unhappy or if there is a problem?
If you are unhappy, or have a problem during the research, please contact will try her best to answer your questions. If you remain unhappy you can contact (research supervisor) via . If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure.

Who can I contact if I have further questions?
Please contact if you have any further questions.

Appendix M: Consent form

Title of Research Project: Stigma, emotion appraisal and the family environment as predictors of carer burden

Researcher(s):

	Please initial box
1. I confirm that I have read and have understood the information sheet dated 07/02/2016 (version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	☐
3. I understand that data from the questionnaires I complete will be part of this study without giving my name or disclosing my identity.	☐
4. I understand that no information from my completed questionnaires will be shared with any other participant in the study.	☐
5. I agree that anonymised data from the study may be used in future ethically approved studies	☐
6. I understand that data from the study may be looked at by regulatory authorities and by persons from the Trust where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data	☐

Name of participant	Date	Signature
Name of researcher	Date	Signature

The contact details of the researcher that will be carrying out the research are:

Appendix N: Multiple regression analysis for initial six predictor model

Multiple regression analysis results for six predictor model

	B	SE B	*B*	*F*
Step 1				
Constant	48.74	1.49		
Gender	-9.62	2.95	-.32**	10.63**
Step 2				
Constant	42.83	2.05		
Gender	-8.31	2.77	-.27**	
Group	9.59	2. 45	.36***	13.76 ***
Step 3				
Constant	-4.03	6.34		
Gender	-4.67	2.25	-.15	
Group	5.48	2.01	.20**	
EOI	1.55	0.2	.58***	33.91 ***
Step 4				
Constant	-5.89	6.13		
Gender	-4.21	2.16	-.13	
Group	4.76	1.94	.17*	
EOI	1.14	0.24	.42***	
CC	0.53	0.17	.26**	30.14***
Step 5				
Constant	-8.79	6.99		
Gender	-4.07	2.16	-.13	
Group	4.66	1.94	.17*	
EOI	1.11	0.24	.42***	
CC	0.51	0.17	.26**	
Stigma	0.24	0.27	.06	24.20 ***
Step 6				
Constant	-7.77	7.07		
Gender	-4.09	2.16	-.13	
Group	5.06	1.99	.19*	
EOI	1.13	0.24	.42***	
CC	0.55	0.17	.28**	
Stigma	0.25	0.28	.07	
PTEQ	-0.16	0.17	-.08	20.33 ***

Note. R^2=.10 for step 1, ΔR^2=.13 for step 2 ($p < .01$), ΔR^2=.30 for step 3 ($p < .001$), ΔR^2=.045 for step 4 ($p < .01$), ΔR^2=.004 for step 5 (*ns*), ΔR^2=.005 for step 6 (*ns*). *** p <.001, ** p<.01, * p <.05.